# **Reason Behind the Migration of People with Spinal Cord Injury**

(SCI) after Rehabilitation



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*This thesis is submitted in total fulfilment of the requirements for the subject RESEARCH 2 & 3 and partial fulfilment of the requirements for the degree of:* 

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# Statement of authorship

Except where it is made in the text of the thesis, this thesis contains no material published elsewhere or extracted in whole or in part from a thesis presented by me for any other degree or seminar. No other person's work has been used without due acknowledgement in the main text of the thesis. This thesis has not been submitted for the award of any other degree in any other tertiary institution. The ethical issue of the study has been strictly considered and protected. In case of dissemination of the findings of this project for future publication, the research supervisor will be highly concerned, and it will be duly acknowledged as an undergraduate thesis.

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# Dedication

This study wholeheartedly dedicated to my family who have been the source of my inspiration and gave me all the support I needed.

Then I humbly dedicate this study to the enhancement of Occupational Therapy students in research work.

Finally, most of all to my creator Almighty Allah, the author of knowledge and wisdom who made this possible by me.

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# List of Abbreviations

- **CRP** Center for the Rehabilitation of the Paralysed
- LMIC Low- and middle-income countries
- NTSCI Non-traumatic SCI
- **QOL** Quality of life
- **RTAs** Road traffic accidents
- **RTW** Return to work
- SCI Spinal Cord Injury
- SwiSCI Swiss Spinal Cord Injury Cohort Study
- **TSCI** Traumatic SCI

Abstract

#### Background

In Bangladesh, spinal cord injury (SCI) is a severe neurological disorder that is either violent or non-traumatic, unexpected and devasting, and handled via history. Spinal cord injuries are becoming more common by the day. In Bangladesh, many post-rehab SCI patients move to their homes near CRP. People with SCI not only suffer from physical complications that require appropriate treatment facilities, but also face psychological problems caused by the stress of losing or looking for a job. They also think about how do societies react and how do families support them? Most important issue that how will they move independently, or how can they live alone without friends? Many complex ideas serve as reinforcements for migration to new areas. However, the phenomenon of migration after rehabilitation is complicated by a number of elements, making their social inclusion almost impossible to anticipate, thereby decreasing their effectiveness.

#### Purpose

The purpose of the study was to explore the reasons behind the migration of people with SCI near the CRP area after rehabilitation.

#### Methods

Qualitative study design using a phenomenological approach to conduct this study. There were ten participants participated who had SCI and currently live around CRP area. A face-to-face interview was done with open ended interview questions with participants and recorded on devices. The data had been analysed by Thematic analysis process.

#### Results

Accessibility of environment for movement, good relationships with family and friends, searching for job or employment, and need for proper treatment facilities were the most common facilitating factors found for migration of people with SCI. In general, the people from rural area faced a lot of barriers as well. They can differentiate the difference between the previous place and the current place's facilities and those facilitators help the people with SCI take the decision to migrate to a new place.

# Conclusions

The findings suggest that the environmental accessibility and psychological support can have an impact on migration, and the resources from government agencies or social agencies, increasing of job facilities for person with disabilities, social awareness can be useful if people know how to access to them and make life better.

## Keywords

Reason of migration, migration after rehabilitation, people with SCI.

# **CHAPTER I: Introduction**

# **1.1 Background**

In Bangladesh Spinal cord injury (SCI), is either traumatic or non-traumatic, sudden and devastation and debilitating neurological condition addresses through the history. According to Rahman et. al. (2017) The occurrence of spinal cord injury is increasing day after days with an annual rate of 15-40 cases per million with male predominance and a leaning of affecting the low-socio economic group. SCI fall on mostly young- and middle- age adults, and the recovery depends on the type and severity of lesion, rehabilitation time, and individual performance how effectively he/she completes every day task. Still, W.M. Marcel (2014) stated that SCI evermore is a major life events that cause to perform serious physical disability and a large number of secondary health conditions (SHCs), the most being pain, bowel bladder regulation difficulty, muscle spasm, fatigue, heart burn, and osteoporosis . According to Akhlasur et. al. (2017), spinal cord injury poses profound impact on the economy both personal and national, as the condition itself additionally the complication led to significant increase of cost. Moreno et. al. (2017), expressed that Individual with SCI has low employment rates and crate freight for the patient as well as family members and also for the society. SCI causes anguish for those are injured and often also for the families who are financially dependent on them. The loss of income and additional medical and ongoing costs associated with the injury place a massive financial impact on families. No wonder, therefore, SCI in Bangladesh and other low- and middle-income countries (LMIC) often put families into outmost poverty (Hossain et al., 2019).

Middelton et. al. (2004) stated that SCI results not only subversive changes in person's physical functioning and independence but predisposes the individual to various secondary complications in all respects of life, which may interfere with health and well-being, social activity, productive employment and quality of life (QOL). According to Franceschini et. al. (2003), there are many different perspectives to consider when dealing with patients with SCI, which cover different domains in the literature, including clinical, psychological, social and relational, occupational, and environmental issues, focusing on the macro effects, and on more specific outcome. According to Bell et.al. (2016), SCI population in rural areas often uses medical care less frequently than those in urban areas, these inequalities arise from a number of predisposing factors such as age, race, and perception of quality of life. Additional enabling factors related to health care utilization is travel time and distance between patient and providers which bring out the thought of migration for rehabilitation of families with SCI.

Many studies on SCI focuses on migration of families dealing with spinal cord injury and took constructive rehabilitation and other factors. that point out by a study on a population of over 2000 spinal cord patients, this parameter linked with several factors. such as gender, years passed away since the injury, degree of mobility, occupation, and level of social integration. However, despite these variables, all patients consist of a complete reorganization that affects not only the episode of the injury itself, but also physical function, as well as expectations, plans, relationships, and the external environment (Frenceschini et. al.2003).

#### **1.2 Justification of the Study**

Purpose of these study is to explore the reason behind the reasons associated with migration or facilitate for migration of families with SCI after rehabilitation. Since there is not much study done in the context of Bangladesh about this topic before, the researcher has no significance advantages or disadvantages to show. One the other hand, internationally there has been few studies on post rehabilitation information and migration after SCI. Therefore, the researcher is interested to find out the reasons those are related with migration or changes in life style or residential location change of person who took rehabilitation service from Center for the Rehabilitation of the Paralysed (CRP) inpatient SCI unit.

The researcher thinks this study will start anew to learn about the living experience of the people with SCI and will find out the reason behind their migration in new place. As all Professionals will be able to know the reasons of migration so they can holistically think the dimensions of treatment, they also will be known how effectively the person reintegrated in the community, or the barriers in his community made him come to this place (CRP) again. It helps professionals ensure that the client's social advocacy takes care of how much accessibility and social rights they deserve. The therapist can then identify the need for an appropriate treatment facility with an appropriate health environment by identifying other medical institute to ensure appropriate rehabilitation services.

# **1.3 Operational Definition/ Definition of Key Words**

## Migration

This term refers the situation when people with spinal cord injury leave their home town to settle around CRP after completing their rehabilitation.

## Rehabilitation

In this study rehabilitation refer as care for people with SCI by which they can improve or regain the physical, mental and / or cognitive (thinking and learning) abilities which need for daily life and improve daily life and functioning and also gain skills through vocational training for employment.

#### **Spinal cord injury (SCI)**

A spinal cord injury is the damage at the end of the spinal canal of any part of the spine or nerve often result in permanent changes in energy, sensation, and other body functions underneath the site of the injury.

#### Paraplegia

Paraplegia is a kind of paralysis that affects most lower-body motions and may be unable to move legs, feet, and occasionally their abdomen on their own. Some people, however, suffer from partial paraplegia when only one leg is paralyzed.

#### Tetraplegia

Tetraplegia is one of the most severe kinds of paralysis, affecting all four limbs as well as the chest, belly, and back in some persons.

# CHAPTER II: Literature Review

## **2.1 Introduction**

The experience of migration after rehabilitation can be very important, particularly life changing event as significant as sustaining spinal cord injury (SCI).

This chapter will present the relevant literature on this topic by starting with a brief introduction to SCI and its diverse impact on individuals, followed by a review of previous research carried out in the particular areas of residential migration of person living with SCI. The following databases has been used for searching: PUB MED.gov, google scholar.

The result of literature searching is given in figure:

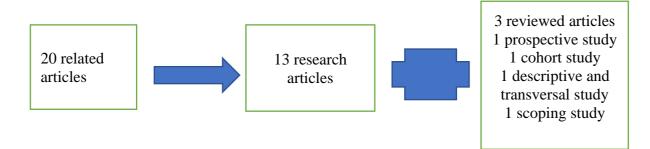


Figure 1. Number of reviewed articles and article type

The information corresponding to the author, year of publication, country of origin and context (where the study was conducted), journal, aims/purpose, and sample size (if applicable), methodology/methods (study design and measures), and key findings that relate to the study questions have been extracted during the data extraction step for literature review.

#### **2.2 Incidence and prevalence of SCI in Bangladesh**

Following to the World Health Organization, the estimated global prevalence of SCI is between 250,000 and 500,000 new cases per year (WHO, 2013). A systematic review article stated that the estimated SCI incidence worldwide varies from 3.6 to 195.4 cases per million (Jazayeri et al., 2014). On the other hand, a hospital based prospective study reviewed that most of the clients were from rural areas, with no or minimum education. Data was gathered from 600 SCI cases in five Bangladeshi hospitals. This study said, poor Occupational safety measure, indigent roads and mixed traffic, with transport users' drivers are reluctant to use seat belts that is in Bangladesh which is substantially populated developing country. This makes the population endangered to SCI. Nonetheless, not much is known about the incidence, prevalence and epidemiology of SCI in the country (Razzak & Roy at el.2016).

A retrospective study was conducted in Bangladesh and the selected data was from medical records of the Centre for the Rehabilitation of Paralyzed (CRP) between January 2012 to December 2014. The study said, In south Asia, Bangladesh is a poor but developing country sustain a great deal of socio-economic problem arising from spinal cord injury and its health-related complications as evident from the yearly rate of admission at specialized center like Centre for Rehabilitation of the Paralyzed (CRP) (Rahman et al., 2018). A cross-sectional study with 410 wheelchair-dependent persons of Bangladesh reviewed that SCI has severe financial consequences for people and their families in Bangladesh, and it is a major source of extreme poverty. This is due to the fact that the majority of individuals who are wounded are young people who are the primary breadwinners in their households. This study included 410 wheelchair-dependent persons (Hossain et al., 2019).

#### 2.3 Reason behind migration after SCI

Since not much study about this topic has not done before, researcher had come up with related researches & studies and find out the possible reasons for the migration of person and family suffering with SCI in different cultures. The researcher had found some relevant themes from different studies which are considering important in the life of people with spinal cord injury.

#### **2.4 Emergent themes from reviewed articles**

#### A. Basic needs

#### Financial issues

A previous research based on cross-sectional data from the Swiss Spinal Cord Injury Cohort Study (SwiSCI), stated that depending on where SCI people live, people are more or less likely to experience financial difficulties. Because financial hardship has been found to have a detrimental impact on health outcomes, the fact that it varies by location means that certain people are at a significant disadvantage because of where they live. This study conducted by collecting data records between 2011 and 2013 and includes information from 1549 people with SCI aged 16 and above (Barzallo, 2018). On the other hand, a qualitative research approach was conducted with 40 adults with SCI from a northeastern city in China with focus group discussion. This study explain that financial security meant having enough money to meet basic requirements like food, clothes, and shelter, as well as to cover medical expenses, financially support one's parents, and engage in social or leisure activities (Hampton & Qin-Hilliard, 2004). Although a hospital based prospective study reviewed that most of the clients were from rural areas, with no or minimum education. Data was gathered from 600 SCI cases in five Bangladeshi hospitals. This study stated that several numbers of people were married of the families were of the nuclear type and main family members were uneducated. The mean monthly income of the clients or their families was very low only and expenditure was higher than the income (Razzak et al., 2017).

#### *Employment*

A qualitative research which included 18 patients by purposive sampling in Thran and Iran, and the participants stated that adjusting to a new condition was challenging due to the obstacles in place. This study includes a lack of financial means. This is mostly due to a reduction in work opportunities (Babamohamadi et al., 2011). And a qualitative study of Brazil with 60 people, where found employment could be a hindrance for SCI people (Blanes et al., 2009).

#### Environmental accessibility

Previous studies evaluated lack of facilities, inaccessibility to public areas, a lack of appropriate equipment, transportation issues, inaccessible buildings, and structural and physical hurdles are among the most significant barriers to social involvement for individuals with SCI (Babamohamadi et al., 2011). A qualitative pilot study of southern USA stated that accessibility could be a facilitator to achieve decision of return to work (RTW) (Wilbanks & Ivankova, 2015). This statement is supported by another qualitative study of Botswana which reported lack of accessibility as a barrier to day-to-day activities of people with SCI. Thirteen community-dwelling people with a SCI who have been living with it for at least two years took part in the study. and the findings highlighted the relevance of personal resources, family support, and better accessibility in facilitating social inclusion. The stigmatization of people with impairments has been documented, however there are few instances from Southern Africa (Löfvenmark et al., 2015).

#### Rural and Urban Living of person with SCI

A study from BMC Health service research journal with participants in SwiSCI were predominantly recruited through three out of four specialized SCI-rehabilitation centers and institutions that are connected to these centers. It found that people with SCI seem to place such a high value on having access to adequate health care that they are able to select their residential location based on local health care availability in Switzerland. Participants in SwiSCI were predominantly recruited through three out of four specialized SCI-rehabilitation centers and institutions that are connected to these centers. To conclude rational People with SCI were more likely to live in urban regions, in areas with a high density of outpatient physicians, and close to specialized SCI centers than the general population (Ronca et al., 2018). A Canadian study from the journal Neurotrauma, published a cohort study with participants of rural 65 and urban 273. The goal of this study was to see if environmental obstacles, health status, and quality-of-life outcomes differed between individuals with SCI living in rural and urban environments. Interestingly no significant outcome has been found through this study. Some of the people migrated from rural to urban after traumatic spinal cord injury (tSCI) (Glennie et al., 2017).

#### Treatment purpose

A study of Switzerland said, People with SCI appear to place such a high value on having access to adequate health care that they are prepared to choose their residence location based on the availability of such treatment (Ronca et al., 2018). And another study of Switzerland stated, healthcare providers are readily available and accessible. The country enjoys a distinct advantage in terms of the number of hospitals and specialist clinics available (Barzallo, 2018).

As a result, the literature describing financial independence depends on location and sometimes education that helps people lead a better life. This document emphasized that people with SCI move to convenient locations for employment, access to the environment, and appropriate therapeutic purposes.

#### **B.** Psychological needs

#### Relationship

A qualitative study of Botswana stated that family and friend support, as well as staff and peer assistance, are key components in creating a strong self, which has an impact on identity, happiness with one's circumstances, and social inclusion (Löfvenmark et al., 2015). Similarly, a qualitative study of a Canadian cross-sectional survey with 1549 adult with SCI, which stated that peer support for people with SCI is crucial for increasing involvement and overall happiness. Individuals who have a lot of unmet SCIrelated demands are more likely to seek peer assistance (Sweet et al., 2015). In the same way an Iranian study highlighted the assistance that young individuals recovering from SCI got from their parents, friends, and other people with SCI was crucial in helping them manage with their problems (Babamohamadi et al., 2011).

#### Social acceptance

Although many studies have shown, that religious beliefs and a spiritual attitude on life have been identified as one of the most important elements in patients' ability to cope with their disease (Babamohamadi et al., 2011). The study of China stated people who have suffered a spinal cord injury are commonly excluded from social and community activities, either because others do not want us or because they are terrified of rejection (Hampton & Qin-Hilliard, 2004). A specific finding highlighted the traditional views of Botswana, such as the notion that disability is a curse or the result of sin, are likely to raise barriers to participation in society, including employment opportunities. Families might block independence by not inspiring or promoting training because of social attitudes and expectations that people with disabilities should be cared for (Löfvenmark et al., 2015). The study of Switzerland stated, the importance of social support in achieving group reintegration and preserving autonomy and freedom cannot be overstated (Ronca et al., 2018).

#### Psychological well-being & self-acceptance

From recent initiative, a study showed a result that suggests self-esteem, selfconfidence, psychological strength, hope, and spirituality are all important following a traumatic experience like a SCI (Löfvenmark et al., 2015). According to the other findings, patients who have strong self-confidence and morale are more likely to reengage with life and manage with hindrance (Babamohamadi et al., 2011). On the other study, participants stated that in order to improve their quality of life, they needed to overcome feelings of self-pity and self-hatred and gain self-confidence (Hampton & Qin-Hilliard, 2004).

The reviewed literature beautifully and importantly explains how important family and peer support are to science people in every aspect of life. This article also talks about societies where social attitudes are important for mental strength to be included in society. Psychological well-being and self-acceptance can increase one's self-confidence and establish independence.

## **C.Others**

#### **Re-admissions**

A reviewed article(meta-analysis) with related studies from 1980 to September 2011 have used to stated emergency health conditions such as neurological dysfunction due to a syrinx and tremor are common reasons for unplanned and unavoidable admissions (Mehta et al., 2012). And in a longitudinal descriptive study of Australia used data set records from the NSW Department of Health Inpatient Statistics Collection between 1989–1990 and 1999–2000 with data from the Royal North Shore Hospital (RNSH) Spinal Cord Injuries Database. This study found early rehospitalization rates in people with SCI have been shown to be high, particularly in the first year after discharge, before decreasing for the next 5–10 years before rising later in life. Urinary tract infection, pneumonia, gastrointestinal issues, pressure sores, discomfort, and spasticity are all common reasons for readmission to the hospital in people with SCI (Middleton et al., 2004pages359–36).

#### Associated Conditions and Surgery

The prospective studies stated that at the time of admission, a number of SCI cases were linked to other conditions. The most common complication was a pressure ulcer. Noncontiguous vertebral damage occurred in a small percentage of spinal injury cases (Razzak & Roy et al, 2016).

#### 2.5 Identifying eligible studies

In April 2021, two independent searches on the PUB MED.gov site were performed for the purpose of evaluating the literature related to SCI factors of migration after recovery in the first study of this thesis. The following criteria were used to choose the articles for this literature review:

- In order to obtain a detailed understanding of the work done in the field of SCI factors of migration, both qualitative and quantitative papers were submitted.
- Between the years 2002 and 2020, papers were written. Since studies conducted prior to this time span may not have been affected by the 2001 ICF components of participation, this is the case.
- publications from a variety of health professions.
- Owing to a lack of translation resources, papers are only written in English.

- Papers with samples of SCI adults aged 16 and up, since the focus is factors affecting the relocation of SCI families.
- Papers that primarily rely on information from SCI patients, such as interviews, surveys, or retrospective results.

In applying the above inclusion criteria, the first search used the following set of keywords: (spinal cord injury, reasons\*, migration\*, after\*, rehabilitation\*).

The second search was conducted to explore literature relevant to the experience of factors of migration after SCI, and hence used a different set of keywords: (spinal cord injury, migration\*, due\* to\*)

From 14 hits, the papers which PUB MED.gov rated as the most relevant were reviewed, and 6 of these met selection criteria. The remaining papers were excluded either because they did not meet the above criteria or for the following reasons:

 Not directly related to the research topic under investigation. For example, papers investigating SCI medical/clinical trials or papers exploring surgical approaches, no place for a wheelchair.

# **CHAPTER III: Methodology**

# 3.1 Research aim, objectives, and questions

# **3.1.1 Research questions**

What are the reasons of the people with spinal cord injury (SCI) to migrate around Centre for the Rehabilitation of the Paralysed (CRP) after rehabilitation?

# 3.1.2 Aim

To explore the reason behind the migration of people with spinal cord injury around

CRP.

# 3.1.3 Objectives

- To explore the basic needs of SCI for migration after rehabilitation.
- To explore the psychological needs after rehabilitation.
- To explore the purpose of his/her life after rehabilitation.

# **3.2 Ethical consideration**

# **3.2.1 Informed consent**

Ethical considerations were implemented to avoid ethical problems.

- Researcher got permission from the Institutional Review Board (IRB) of Bangladesh Health Professions Institute (BHPI), an academic institute of the Centre for the Rehabilitation of the Paralyzed (CRP) to conduct the research.
- After getting the permission from IRB and the Occupational Therapy department, the researcher went for the permission of CBR department for collect informative data of required population.

- Participants information sheet had been described to the participants before the interview followed by taking inform consent written in Bangla. The student researcher documented their consent by their signature before recording the interview.
- Participants were made aware of the withdrawal procedure.
- The participants' confidentiality was secured and safe guarded by the researcher. The interviews were only accessible to the researcher and the supervisor, as mentioned in the information pages.

## **3.2.2 Unequal Relationship:**

• There was no prior connection between the student researcher and research participants. No power relationship was implemented through any kind of sources or connection. There wasn't any biasness in the study.

## 3.2.3 Risk and Beneficence:

• The participants were well aware that they would not be compensated monetarily. They didn't skip any work time or duties even when they came in for the interview. The interview took place at a time that was convenient for the participants. Participant's information is safe and secure and there wasn't be any risk of participants during interview or another time.

## 3.3 Research design

Researcher used phenomenological approach of qualitative design. Because in phenomenology, analysis aims to describe and interpret the meaning of an experience, often by identifying essential subordinate and major themes. Finding for common themes in an interview and across interviews, involving research participants. The result of phenomenological research is a detailed explanation of the problem that captures the essential meaning of the "living" experience. The most important criterion is the participant's experience with the phenomenon within the framework of the study (Moser & Korstjens, 2017). Phenomenology is a unique philosophy that enables us to competently and appropriately respond to each individual in their time, place, and situation (Errasti-Ibarrondo et al., 2018). Phenomenology helps us understand the complexity of learning, behavior, and communication. It also helps unleash the importance of a person's perspective, knowledge, and living experience (Neubauer et al., 2019).

As the researcher wanted to investigate the phenomenon which may describe and interpret by the participants about their living experiences. So, it was a suitable research design for this study.

#### 3.4 Study setting

Qualitative method design focuses on ordinary events in natural settings. The study focused on the participants who have primarily received rehabilitation services from CRP's SCI unit and living around CRP residential area or so. So the researcher conducted the interview to observed and interacted with the participant's in their own convenient place near CRP where they felt comfortable.

### 3.4.1 Period

April 2021- February 2022

### **3.5 Sampling Strategy**

#### 3.5.1 Sampling techniques and size

10 participants had been selected by convenience sampling method.

Convenience sampling is most commonly used in clinical research where patients who meet the inclusion criteria are recruited in the study. The advantages are that they are most commonly used, less expensive and there is no need for a list of all the population elements (Acharya et al., 2013).

### 3.5.2 Inclusion and Exclusion criteria

Inclusion criteria:

- SCI patients who received in-patient rehabilitation service from CRP and relocated to a new place from their home.
- Both male and female person with SCI.
- Person with SCI, who are 18 years old or above.

Exclusion criteria:

- Person with SCI who has received rehabilitation from the outpatient unit, CRP.
- Person with SCI who have diagnosed mental illness or cognitive impairment.

## **3.6 Participant's Recruitment Process**

A list of discharged patients of last 10 years had been collected from CBR Department of CRP. After collecting the list from CBR, the researchers made a short list of SCI patients who were wheelchair obedient. After contacting with participants according to the given contact information, the researchers found 20 patients who were living near CRP. After making that short list, researcher selected about 10 final participants for the study by convenience sampling according to inclusion criteria. The researcher contacted The Spinal Cord Injuries' Development Association Bangladesh (SCIDAB) and received help from the association to find out those listed participants easily. Then researcher contacted them and reached them in CRP area or near CRP to conduct the interview.

## **3.7 Data collection**

#### 3.7.1 Data collection method

After getting the permission from the authority of CRP, the student researcher went for two field test data collection. After field test, researcher included some new questions into the interview question and then the final data collection had started. According to student researcher previous plan, information was taken from 10 adult people with spinal cord injury. Semi-structured open ended in-depth interview had conducted by an interview question. In that case, most of the question was open ended so that the researcher could find out the objectives of the study and used a tape recorder to record the exact answer of the candidates by taking candidates permission. When the main question was not enough, student researcher used probing questions regarding the question topic. All interviews conducted in Bangla language, so that candidate could understand and response properly. And the face-to-face interview helped the student researcher to see the emotions, expressions, gesture, movement of the candidates. Each interview took about 10-25 minutes.

# **3.7.2 Interview instrument**

During interview time, investigator used -

• Self developed interview question hard copy which required 8 main questions with some probing questions. And all the questions were included regarding participant's life experiences before & after rehabilitation from CRP.

• The question details can be found in Appendix C.

#### **3.8 Data analysis**

-Thematic analysis process was used to data analysis.

Thematic analysis is a research method in which the student researcher attempts to learn anything about people's perspectives, ideas, experiences, or values from a set of qualitative data by interview transcripts. According to Braun & Clarke (2021,p.xx), thematic analysis is a data analysis method that helps a researcher to identify themes and patterns of meanings across a dataset in relation to a particular research question(s). They further state that this method can be used to analyze almost any kind of qualitative data such as interviews, focus groups, and qualitative surveys, using larger or smaller datasets.

The data was evaluated by the researcher using Braun and Clarke's six phases of theme analysis.

- After translating the data, the first step was to get to know the data. The researcher gets an overview of all the data collected before starting to analyze individual items.
- The researcher reviewed over the transcripts of each interview at this point and marked anything that stood out as pertinent or possibly intriguing. In addition, any phrases and sentences that fulfill the requirements have been highlighted. After reading the text, the researchers organize all of the information into coded categories.

- When all the data had been initially coded and collated, the researcher took the long list of the different codes that were identified across the data set. Essentially, the researchers began to analyze the codes and consider how different codes might combine to form an overarching theme. Researcher wrote the names of each code on a separate piece of paper and organized them into a theme-map.
- During reviewing the themes, the researcher split them up, combined them, discarded some of them, and created new themes, which makes the themes more useful and accurate.
- In the fifth step, the researcher created a map based on the data. The researcher's mapping of the themes aided in connecting the tale to the research. All of the associated codes beneath each theme assisted in identifying a theme's description.
- Finally, When the researcher had a set of fully worked-out themes, the researcher started the final analysis and write-up the statement. The researcher wrote the statement in the result section according to the theme in turn. The researcher described how often the themes come up and what they mean, including examples from the data as evidence.

## 3.9 Trustworthiness/ Rigour

The participants are in coherence with the research inclusion criteria. They sat for the interviews in their spatiotemporal convenience. While conducting the interviews they were surrounded by their peers who corroborated their answers. Moreover, the body languages and gestures were positive indicating that they were relaxed throughout their

respective interviews. And, most of the participants were members of SCIDAB, so it showed the authentication of participants identity. Finally, the participants were fully unknown to the researcher so there was no issue of biasness.

# **CHAPTER IV: Results**

The interviews with participants on their experiences with migrating following rehabilitation revealed four significant themes. Emergent Themes and their corresponding sub-themes are listed below:

# Table 1. Table of emergent themes and sub-themes of result

Themes	Sub-themes
1. Accessible daily life services lead for migration	Home accessibility Community accessibility
2. Migration for income generating opportunity	Employment Financial issues
3. Desired psychological satisfaction influence for migration	Relationship with love & belongings Social attitude Self- fulfillment
4. Migration for available treatment and medical essentials	Treatment services Medical aids

*Notes.* The survey items read as follows: "Why do most of the SCI people are migrating their home near CRP after rehabilitation phase?"

#### 4.1 Theme One: Accessible daily life services lead for migration

From their interview, it clear that environmental accessibility ensures their safety needs and freedom which enhance their community integration. Most commonly accommodation and community accessibility of CRP area make people with SCI migrated here. To ensure their safety and wellbeing, people with SCI need accessible accommodation to live.

#### 4.1.1 Sub-Theme One: Home/Accommodation Accessibility

Most people in their interviews said that the houses around the CRP are very accessible. One participant said, "I can move around the house by myself. This was done with the help of our landlord. I'd say that the house is 90% accessible."

One of them said that the houses are really wheelchair friendly so they are still here after rehabilitation. But one said he needed a low-cost home. The last statement is obviously connected with financial issues. This statement explain that an accessible environment can be costly as well for some people.

#### **4.1.2 Sub-Theme Two: Community accessibility**

In addition to the house, they also had a great opinion about the community accessibility in the area. As some have said, the environment around CRP, roads, markets, markets or accessible for them. So, they stay here. Another said there is no such accessibility anywhere else. Another said that the CRP hospital is made for the paralyzed, which is a paradise for them. Another said that the urban environment is more accessible than the village so he wants to stay in the city.

One participate said, "I'm in Savar because the houses are wheelchair friendly. Most people like me have to take their wheelchair to the toilet even. Some can walk with additional aid for a little while but most cannot. So that poses a problem."

#### **4.2** Theme Two: Migration for income generating opportunity

Not only for the accessibility of the environment, but also for the benefit of many spinal cord injuries. Employment issues make them free from mental stress of supporting their family. Financial independency mostly depends on the employment or work sector. An interviewer said, he was searching for a suitable job for him. That means people with SCI need accessible and suitable job environment for them. So that they can work properly and independently. As they are not getting another accessible environment, they tend to stay near CRP area or in CRP and trying to find a job or start a business there.

#### 4.2.1 Sub-Theme One: Employment

When it comes to employment, we see that few people are engaged in any work or doing business in the vicinity of CRP or CRP. Some people are trying to find a job for them and some are trying for business. But the funny thing is that one is living here not only for his job but also for the job of his parents.

One of them said, "There's always a tension at the back of my mind, mostly about supporting my family. Also, my own future."

#### 4.2.2 Sub-Theme Two: Financial issues

Everyone is trying to make themselves financially independent. Some of them want to start their own business or some of them want to make their business bigger. Although very few people are running their business successfully.

One of them said, "In our country those who don't have money face great problems. I've seen things, bought wheelchairs, clothes, supplies. Loaned a few businessmen too. So yes those deprived of money find it very difficult without money and family." Similarly another person said, "My confidence is sky high. I won't face any problems. Also I'll need financial backing." They do want to be financially self-sufficient and don't want to become a burden to the family.

#### 4.3 Theme Three: Desired psychological satisfaction influence for migration

Psychosocial needs include family relationships, friendships, and social relationships, all of which play a vital role for people with spinal cord injuries. However, despite the hardships, most of the friends of the previous place did not have much contact with them. But they are happy to have friends like them here. One of them also mention about social support beside family and friends support. As the previous friends didn't contact, they need a new circle or group to added who will accept their situation like this. Of course, it's also a major reason to migration in CRP area to find a similar group of friends, colleagues and supporter.

#### **4.3.1 Sub-Theme One: Family and friend's support**

Most of them said friends like them(disabled) understand them a lot. Everyone here is looking for everyone, everyone is talking to everyone. But there was no one to talk to in the area of the former residence. Some people said that they need a lot of family support in their life. In this context, one said, "It's very difficult without money and family. Not necessarily a wife, but a support system. There are many of us who have married but the wife left them. Many stayed after seeing the state they're in."

One of them said that he was living here alone without any help from his family and his friends here started his business with some financial help.

Another person said, "The only thing I need is support. The things I cannot do, or my body gives up then I'll need some support to get it done."

#### 4.3.2 Sub-Theme Two: Social attitude

Individual rights and positive social attitude are guaranteed in an inclusive society founded on social justice. As the people with SCI face the negative reaction from society and friends, they mostly try to be with a positive environment like CRP area. Where there are so many people are living, working and enjoying their life with one another. And this positive environment makes them confident, ensure their selfacceptance, increase their confidence to establish in life. The positive and friendly behavior of their friend circle increase the social participation of people with SCI.

Social attitudes may have motivated people with spinal cord injuries to stay together in one way or another. Most of them said that there are many disabled people like them here and they don't think of themselves as inferior. One of them stated, "During my vocational training, I had decided not to go back home. Because there was no wheelchair person or friends to come and chat with me. People can't live alone. So, I rented a flat here to stay."

Even one of them does not go in one's own village because of his inferiority complexity. When he sees healthy friends, he becomes mentally depressed.

Interestingly most of them in their spare time, they come to CRP just to talk to everyone, to spend time, to attend indoor and outdoor games. This association and the positive attitude enhance their social participation. One of them said, "After having breakfast, I come to CRP. Then I look for work, interact with the familiar faces. There are some common spots where I am usually seen, and that too with the same people. That's pretty much everything."

Social inequality is a very common problem in our country. And disabled people have to face many kinds of stress or other problems because of this. Most of them said in the interview that their friends give negative reaction after their accident. Once said, "The negatives are the environment. People think that because we are the disabled staff, we aren't that educated. So, we're underestimated often. This is the one thing I find disturbing." Another participant said, "It will be good for people like us, if we get job opportunity in various company." By eliminating social inequality and increasing all kinds of benefits for the disabled in Bangladesh is very necessary. Then the disabled will no longer be a burden.

### 4.3.3 Sub-Theme Three: Self-fulfillment

Self-fulfillment or personal growth vary person to person. Some of people want better job, some of them want education, some of them want better business. But interestingly some of the people just want to accept their life situation. According to these interviews, social equality, social support is connected with self-fulfillment. Because who does not have family but want to start a business, he needs social or government support. One the other hand, who are mentally confident but not getting any suitable job offer for them to, they of course need the proper government support. Mostly important to accept their situation of life. When they find their potentiality, they will be more confident and more dedicated in life.

Most of them want to improve their own business or job. Some of them want to finish their own studies. Some of them want to educate their child for selffulfillment. However, some people have wanted better position in job for the betterment of life. One who has not any family support, he needs of course social welfare to do betterment of life and his business. But one said everyone to be self-reliant and it's very important for them to accept their situation for better future and also for growing more confidence. Very few people said that they really have no plan in life. One of them from the few people who doesn't have plan said, "I couldn't complete my HSC. If I complete my Master's even we still have no future. Not me, this is true for people like me. We have friend who are educated but they're not getting the jobs that they deserve." virtue. Many struggles with accepting the reality. But we can't do that at all. If we do this then we can't move on. It just leads to more harm." Though he doesn't have any work plan for future but according to his statement he cleared that his self-acceptance and tolerant give him the best achievement of life.

## 4.4 Theme Four: Migration for available treatment and medical essentials

Treatment Services and Necessary Medical Aids also an important need for SCI people, which wasn't easily available for some participants. As those essentials were suggested them to use or to take the treatment service, people with SCI had to migrate near CRP for easy reaching.

#### 4.4.1 Sub-Theme One: Treatment Service

Some people needed therapy for various physical complications. One said the CRP service did not allow him to return. He said, "CRP and the people associated are wonderful. Often people like me get depressed. CRP offers them counseling, invite in programs. That's how our hearts were always happy. This is the main reason of not going anywhere else actually."

#### 4.4.2 Sub-Theme Two: Medical aids

A small number of people said that they did not get the medical aids they needed in their respective areas which are available in CRP. This is another reason for their change of residence. He said, "After the accident I had many requirements, mostly accessories. Those are not available throughout the country. The local pharmacies didn't sell the accessories that I needed."

So, it's clear that, availability of proper treatment service and medical aids ensure their good health and well-being.

## **CHAPTER V: Discussion**

As the goal of the study is to determine the reason for the migration of the people with spinal cord injury, the researcher has attempted to determine the reason for the change of residence by learning about their requirements. People strive to meet various wants or requirements since they have different sorts of requests. People participate in a variety of behaviors, beginning with relocating their house, in order to match the need. The findings revealed a distinct dimension of demands for persons with SCI, whose needs aided them in making the decision to relocate following recovery.

The importance of environmental accessibility, interaction with family friends, and social attitude were the important aspects that permitted persons with SCI to relocate their house after recovery, according to the findings of this study. When it comes time to talk about accessibility, it comes up vastly. The studies of Iran, Southeast USA, and Botswana stated that accessibility ensures the social involvement (Babamohamadi et al., 2011) or facilitate social inclusion of people with SCI, and a lack of accessibility is the barrier for those people (Löfvenmark et al., 2015). This major statement is largely comparable to the findings of this research. The study's findings demonstrate the relevance of accessibility in the lives of the participants. People migrating from their homes to metropolitan locations for accessible treatment was discussed in the Switzerland study of rural and urban communities. The Canadian research, on the other hand, stated the exact reverse. There were no substantial shifts in migration from rural to urban regions, according to the Canadian research (Glennie et al., 2017). People are now migrating to metropolitan regions in search of a better living, according to this research.

The majority of them acknowledged the need for accessibility in their homes, communities, and workplaces. Because a well-accessible environment assures their protection while also allowing them to exercise their independence. Because Bangladesh is a developing country, not every location is accessible to everyone. As a result, persons with SCI move to residences near the CRP area in quest of a better accessibility.

According to two studies from Switzerland, people with SCI appear to place such a high value on having access to adequate health care that they are prepared to choose their residence (Ronca et al., 2018) and the treatment services that are available (Barzallo, 2018). According to the result of this study, people with SCI migrate to their homes near CRP for treatment services. They also come here for the availability of medical aids. As proper treatment services and medical aids are important and mandatory for people with SCI, they decide to come to the available place to fulfill their needs.

Parts of the findings of this study might be applied to various situations, such as inaccessibility issues, unfavorable societal attitudes, and the necessity of personal resources and a supporting family. In underdeveloped countries, however, the deciding role of family support and living conditions, as well as having a consistent income, is likely to be more important.

When it comes to relationships, family, friends, and social ties, in that order. This psychological needs related information was cited in the majority of the published pieces. Such as a research in Iran emphasized the support that young people recovering from SCI received from their parents (Babamohamadi et al., 2011), while a cross-sectional survey in Canada found that peer support for persons with SCI is critical for

boosting engagement and overall satisfaction (Sweet et al., 2015). Similarly, according to the study of Botswana, family and friend support, as well as professional and peer aid, are all important components in developing a healthy self (Löfvenmark et al., 2015).

According to the findings of this study, persons with SCI require enough family and peer support to live a happy life, which will make them psychologically happy and help them boost their social inclusion.

All of the above were considered important in this study, and a lack of them resulted in a significant reduction in the chances of having a strong self and experiencing social inclusion.

Traditional Botswana beliefs, such as the belief that disability is a curse or the result of sin, (Löfvenmark et al., 2015) where a study of China said disability are likely to create barriers to participation in society, including employment opportunities (Hampton & Qin-Hilliard, 2004). And according to a Swiss research, the importance of social support in attaining group reintegration and maintaining autonomy and independence (Ronca et al., 2018).

Where previous statement explained that the family & peer support help a disabled person for social inclusion, and it's also an important finding that a positive societal attitudes motivate persons with SCI to migrate their homes near the CRP after rehabilitation. That means the migration may occurs because of the similar disabled group, positive attitude among all the CRP people in Bangladesh. They found new pals during recovery who are similar to them and who bring mental peace. As a result, individuals choose to stay with people who are similar to them and leave their prior residence in order to avoid being assessed by strangers or relatives.

Self-acceptance difficulties were discussed in a few research. People must accept

themselves in order to grow their lives, according to the findings of this study, which provides them more bravery to attain their life goals. Self-acceptance aids the person with SCI in receiving self-acceptance. However, some people use financial or occupational advancement as a method of achieving self-satisfaction. However, for some people, the process of self-acceptance and self-development is difficult. The truth is that psychological strength makes everyone strong, even if they are physically unwell.

In terms of employment, researchers discovered in a previously reviewed article that a study conducted in Tehran, Iran, concluded that the place of work and a lack of job opportunities are to blame for their financial problems (Babamohamadi et al., 2011), where as a study conducted in Brazil concluded that employment could be a barrier (Blanes et al., 2009). Furthermore, society has a negative attitude against employing persons with disabilities, which is the primary cause of financial troubles among this population. Findings from this study suggested that people with SCI, like others, require additional career options. They are experiencing emotional distress as a result of their inability to find suitable employment that will allow them to support their families. A participate told once regarding this issue, "If I can contribute something towards my family then that would be my best achievement. That I did something for my family even in this state."

They don't want to be a financial burden on his family. Everyone wishes to be employed or financially self-sufficient.

Financial hardship has been proven to have a negative influence on health outcomes, but because it varies by region, certain people are at a substantial disadvantage because of where they reside, according to a research from Switzerland (Barzallo, 2018). According to Chinese research, Financial security is defined as having enough money to satisfy basic needs as well as to pay medical expenditures, financially support one's parents, and engage in social or recreational activities (Hampton & Qin-Hilliard, 2004). The researcher noticed similarities with this assertion in this investigation. Researchers discovered that persons without money had a difficult time meeting their basic necessities. To be self-sufficient, some people require financial assistance. And some of the folks who are remaining around CRP due of job prospects or because they are attempting to become financially self-sufficient claimed the location is accessible to them. As a result, they are looking for a suitable work with a suitable office, as well as a wheelchair-accessible house. Employment, it turns out, is linked to environmental accessibility for persons with SCI.

## **CHAPTER VI: Conclusion**

#### **6.1 Strength and limitations**

In the past, SCI have been dealt with various problems or obstacles, but no research has been done in Bangladesh on the reasons and experiences of changing their place of residence after their rehabilitation. Since this is the first study of Bangladesh on this subject, many important issues have come to light in this research. This study brought up the idea of not being treated differently by friends and family as a significant topic. This precise attitude by friends and relatives has never been identified as enabling in prior study. This is a topic worth looking into more, since this knowledge might be useful to individuals who are forming a support network for someone who has SCI. Even this study adds to previous research in this area by demonstrating how persons with new SCI prefer to be mentored by people who are similar to them in terms of gender, personality, activities, and, most significantly, injury severity. While finding appropriate environment, job for persons with SCI is more challenging, the data demonstrates that this group has the biggest challenges in terms of social and community engagement, demanding further efforts.

Primarily the limitations of this study were limitations of sample size because of COVID-19 situation and another limitation was limited related literature about this study topic.

#### **6.2 Practice implication**

Government or social agency resources can be beneficial if individuals understand how to use the resources to improve the life of people with SCI. Since the research is being done first time in Bangladesh, more study is needed to enrich it.

## **6.3 Recommendation**

- The government should emphasize the accessibility of the whole community so that people with SCI don't need to leave their own patriarchal home.
- Government and social agencies should increase awareness among the societies thus the people with SCI will no longer become a social barrier.
- The government and society must work together to enhance the environment, provide career opportunities for persons with SCI, and provide opportunities for them to engage in various social activities.

## **6.4 Conclusion**

The study emphasized the importance of physical and psychological needs which work as reinforcement for the participants to migrate near CRP. Participants stated about their life experiences after rehabilitation through explaining those needs and the reason behind the migration. Moreover, the participants also talked about their barriers of previous places. This qualitative study revealed that persons with SCI look for easily accessible daily living services, suitable income-generating opportunities, family, friend & societal support and treatment purpose which are connected with person's post-rehabilitation mobility near the CRP region. As participants stated about their social and physical barriers, they also stated about the feelings to overcome from those barriers to improve their life situation. However, the physical, social and psychological inequity affect psychological processes, lack of self-confidence of SCI people operates as a barrier for changing their life and drive away from social inclusion. It clear that the person with SCI choose to migrate near CRP from their former location for improving their quality of life.

# List of Reference

- 1.Acharya, A. S., Prakash, A., Saxena, P., & Nigam, A. (2013). Sampling: Why and How of it? *INDIAN JOURNAL OF MEDICAL SPECIALITIES*, 4(2), 330-333. https://doi.org/10.7713/ijms.2013.0032
- 2.Babamohamadi, H., Negarandeh, R., & Dehghan-Nayeri, N. (2011). Barriers to and facilitators of coping with spinal cord injury for Iranian patients *Nursing and health sciences*, *13*, 207-215. <u>https://doi.org/10.1111/j.1442-</u>

<u>2018.2011.00602.x</u>

- 3.Barzallo, D. P. (2018). Place of residence & financial hardship: the situation of people with spinal cord injury. *International Journal for Equity in Health*, 17(1), 115. <u>https://doi.org/10.1186/s12939-018-0818-9</u>
- 4.Blanes, L., Carmagnani, M. I. S., & Ferreira, L. M. (2009). Quality of life and selfesteem of persons with paraplegia living in Sao Paulo, Brazil. *Quality of Life Research*, 18, 15-21. <u>https://doi.org/10.1007/sl 1136-008-941 1-9</u>
- 5.Bell, N., Kidanie, T., Bo, C., & Krause, J. S. (2016). Geographic variation in outpatient healthcare service utilization following spinal cord injury. *PHYSICAL MEDICINE AND REHABILITATION*. <u>https://doi.org/10.1016/j.apmr.2016.09.130</u>
- 6.Errasti-Ibarrondo, B., Jordán, J. A., Díez-Del-Corral, M. P., & Arantzamendi, M. (2018). van Manen's phenomenology of practice: How can it contribute to nursing? *Nursing Inquiry*. <u>https://doi.org/10.1111/nin.12259</u>

- 7.Franceschini, M., Clemente, B. D., Rampello, A., Nora, M., & Spizzichino, L.
  (2003). Longitudinal outcome 6 years after spinal cord injury *spinal cord*, *41*, 280-285. <u>https://doi.org/10.1038/sj.sc.3101457</u>
- 8.Glennie, R. A., Batke, J., Fallah, N., Cheng, C. L., Rivers, C. S., Noonan, V. K., Dvorak, M. F., Fisher, C. G., Kwon, B. K., & Street, J. T. (2017). Rural and urban living in persons with Spinal Cord Injury and comparing environmental barriers, their health, and quality-of-life outcomes. *National library of medicine*, 34(20), 2877-2882. <u>https://doi.org/10.1089/neu.2016.4931</u>
- 9.Hampton, N. Z., & Qin-Hilliard, D. e. B. (2004). Dimensions of quality of life for Chinese adults with spinal cord injury: A qualitative study. *Disability and Rehabilitation*, 26(4), 203-212.

https://doi.org/10.1080/09638280310001639704

10.Hossain, M. S., Harvey, L. A., Islam, M. S., Rahman, M. A., Liu, H., & Herbert,
R. D. (2019). Loss of work-related income impoverishes people with SCI and their families in Bangladesh. *spinal cord*, 423–429.

https://doi.org/10.1038/s41393-019-0382-1

- 11.Jazayeri, S. B., Beygi, S., Shokraneh, F., Hagen, E. M., & Rahimi-Movaghar, V.
  (2014). Incidence of traumatic spinal cord injury worldwide:a systematic
  review. *Eur spine j.* <u>https://doi.org/10.1007/s00586-014-3424-6</u>
- 12.Karimia, M., Omarb, A. H. H., & Fatoye, F. (2014). Spinal cord injury rehabilitation: Which way forward. *Neuro Rehabilitation*, 325-340. <u>https://doi.org/10.3233/NRE-141124</u>
- Löfvenmark, I., Norrbrink, C., Wikmar, L. N., & Löfgren, M. (2016). The moment I leave my home – there will be massive challenges': experiences of

living with a spinal cord injury in Botswana. *Disability and Rehabilitation*, 38(15), 1483–1492. https://doi.org/10.3109/09638288.2015.1106596

14.Moser, A., & Korstjens, I. (2017). Series: Practical guidance to qualitative research.Part 3: Sampling, data collection and analysis. *European Journal of General Practice*, 24(1), 9-18.

https://doi.org/10.1080/13814788.2017.1375091

- 15.Middleton, J. W., Lim, K., Taylor, L., Soden, R., & Rutkowski, S. (2004pages359–36). Patterns of morbidity and rehospitalisation following spinal cord injury. *spinal cord*, *42*, 359–367. <u>https://www.nature.com/articles/3101601</u>
- 16.Mehta, S., Hill, D., Foley, N., Hsieh, J., Ethans, K., Potter, P., Baverstock, R., Teasell, R. W., Wolfe, D., & Team, T. S. C. I. R. E. R. (2012). A Meta-Analysis of Botulinum Toxin Sphincteric Injections in the Treatment of Incomplete Voiding After Spinal Cord Injury. *Arch Phys Med Rehabil*, 93(4), 597-603. <u>https://doi.org/10.1016/j.apmr.2011.11.020</u>
- 17.Moreno, A., Zidarov, D., Raju, C., Boruff, J., & Ahmed, S. (2017). Integrating the perspectives of individuals with spinal cord injuries, their family caregivers and healthcare professionals from the time of rehabilitation admission to community reintegration: protocol for a scoping study on SCI needs. *BMJ open*. <u>https://doi.org/10.1136/bmjopen-2016-014331</u>
- 18.Neubauer, B. E., T., C., Witkop, & Varpio, L. (2019). How phenomenology can help us learn from the experiences of others. *Perspect Med Educ*. https://doi.org/https://doi.org/10.1007/s40037-019-0509-2
- 19.Rahman, A., Ahmed, S., Sultana, R., Taoheed, F., Andalib, A., & Arafat, S. Y.(2017). Epidemiology of Spinal Cord Injury in Bangladesh: A Five Year

Observation from a Rehabilitation Center. *Journal of spine*, 6(2). https://doi.org/10.4172/2165-7939.1000367

- 20.Rahman, Z. M., Alam, S. M. L., Gani, M. S., Ahmed, F., Tawhid, A. K. M. M., & Ahmed, M. S. (2018). Demographic Profile of Spinal Cord Injury Patients
  Admitted in a Rehabilitation Center: An Observational Study from
  Bangladesh. *journal of Medical Research and Innovation*, 2(2).
  <a href="https://doi.org/10.15419/jmri.111">https://doi.org/10.15419/jmri.111</a>
- 21.Ronca, E., Brunkert, T., Koch, H. G., Jordan, X., & Gemperli, A. (2018).
  Residential location of people with chronic spinal cord injury: the importance of local health care infrastructure. *BMC Health Services Research*, *18*, 657.
  <a href="https://doi.org/10.1186/s12913-018-3449-3">https://doi.org/10.1186/s12913-018-3449-3</a>
- 22.Sweet, S. N., Noreau, L., Leblond, J., & Ginis, K. A. M. (2015). Peer support need fulfillment among adults with spinal cord injury: relationships with participation, life satisfaction and individual characteristics. *Disability and Rehabilitation*, 38(6). <u>https://doi.org/10.3109/09638288.2015.1049376</u>
- 23.W.M.Marcel. (2014). Definitions of Quality of Life: What Has Happened and How to Move On. *top Spinal Cord Inj Rehabil*, 20(3), 167-180.
   <u>https://doi.org/10.1310/sci2003-167</u>
- 24.Wilbanks, S. R., & Ivankova, N. V. (2015). Exploring factors facilitating adults with spinal cord injury rejoining the workforce: a pilot study. *Disability and Rehabilitation*, 37(9), 739–749. <u>https://doi.org/10.3109/09638288.2014.938177</u>

25.World Health Organization. (2015). *Trends in maternal mortality: 1990-2015: estimates from WHO, UNICEF, UNFPA, World Bank Group and the United Nations Population Division*. World Health Organization.

# APPENDICES

### **Appendix A: Approval Letter**

বাংলাদেশ হেল্থ প্রফেশন্স ইনস্টিটিউট (বিএইচপিআই) **Bangladesh Health Professions Institute (BHPI)** BANGLADESH HEALTH **PROFESSIONS INSTITUTE** (The Academic Institute of CRP) Ref: Date CRP/BHPI/IRB/11/2021/517 14/11/2021 То Irin Sultana 4thYear B.Sc. in Occupational therapy Session: 2016-17, Student ID:122160224 BHPI, CRP, Savar, Dhaka-1343, Bangladesh Subject: Approval of the thesis proposal "Reason behind the migration of people with spinal cord injury (SCI) after rehabilitation" by ethics committee. Dear Irin Sultana, **Congratulations** The Institutional Review Board (IRB) of BHPI has reviewed and discussed your application to conduct the abovementioned dissertation, with yourself, as the principal investigator and Md. Mohsiur Rahman as thesis supervisor. The Following documents have been reviewed and approved: Sr. No. Name of the Documents Dissertation/thesis/research Proposal 1 Questionnaire (English & / or Bengali version) 2 3 Information sheet & consent form. The purpose of the study is to explore the reason behind the migration of people with spinal cord injury (SCI) after rehabilitation around CRP. The study involves use of an interview question to explore reasons behind the migration of people with spinal cord injury around CRP, that may take 45 minutes to 55 minutes to answer and there is no likelihood of any harm to the participants .The members of the Ethics committee have approved the study to be conducted in the presented form at the meeting held at 9:15 AM on 15th September, 2021 at BHPI 29th IRB Meeting. 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, tellathanaen Muhammad Millat Hossain Assistant Professor, Dept. of Rehabilitation Science Member Secretary, Institutional Review Board (IRB) BHPI, CRP, Savar, Dhaka-1343, Bangladesh CRP-Chapain, Savar, Dhaka-1343, Tel : 7745464-5, 7741404 E-mail : principal-bhpi@crp-bangladesh.org, Web: bhpi.edu.bd, www.crp-bangladesh.org

#### **Appendix B: Information sheet and consent form**

## **Information and Consent forms for Participants**

**Research Subject**: "Reasons behind the migration of people with Spinal cord injury(SCI) after rehabilitation."

**Researcher**: Irin Sultana, B.Sc. in Occupational Therapy Department,4<sup>th</sup> year, session:2016-17,Bangladesh Health Professions Institute (BHPI), Savar, Dhaka-1343.

Place of Research: Near Center for the Rehabilitation of the Paralysed (CRP) area, Savar, Dhaka-1343.

## **Episode-1: Information form**

#### **Introduction:**

Myself Irin Sultana, 4<sup>th</sup> year student of B.Sc in Occupational therapy department. It is compulsory for me to conduct a research project in order to complete my educational work. This form will help you decide to participate in the research. It will be presented to you in detail. The information contained in that brochure will help you decide whether or not to participate in the research. There is a need to know more about some of them, but feel free to contact the researcher and Md. Mohsiur Rahman (Lecturer, BHPI), the supervisor of this study.

#### **Research Objectives:**

The purpose of this study is to investigate the causes of changes in the vicinity of the CRP in the place of residence of persons with spinal cord injuries after rehabilitation. You will need to sign a consent form as a participant in this study. Once you've confirmed your participation, I'll ask you some personal and research questions.

#### What are the benefits and risks of participating?

You will not receive any direct financial or other benefits for participating in the research project. In addition, you will not have to take any kind of physical and mental risk due to participating in this research.

### Will the confidentiality of the information be ensured?

By signing this consent form you have given permission to the research staff studying this research project to collect and use your personal information. Any information collected for this research project that may identify you will remain confidential. The information collected about you will be symbolically mentioned. Only researchers and their supervisors directly involved will have access to this information. Symbolically identified data will be used for subsequent data analysis. It is expected that the results of this research project will be published and presented in various forums. In the case of any publication or presentation, the information will be provided in such a way that you cannot be identified in any way without your consent. The data will be collected in a preliminary manner. Individuals will be reserved for a specified period in BHPI's occupational therapy department. At the end of time they will be destroyed in due process.

# **Episode-02:** Consent form

I have been invited to take part in a study entitled "Reasons behind the migration of people with Spinal cord injury(SCI) after rehabilitation." I have read the aforementioned fact sheet or it has been read to me. I had the opportunity to ask a question on this subject and I got a satisfactory answer to any question. I voluntarily agree to be a participant in this study.

Participant Name: Participant Signature: Date: Day / Month / Year

If illiterate \* I make sure the consent form has been read correctly in front of me and I have been given the opportunity to ask questions about the research. I am voluntarily participating in this study.

Participant fingerprint:

Witness Name: Witness signature:

Researcher's Name: Irin Sultana

Researcher Signature: Date: Day/moth/year

#### অংশগ্রহণকারীদের জন্য তথ্য ও সম্মতিপত্র

গবেষনার বিষয়: " মেরুদণ্ডের আঘাতপ্রাপ্ত ব্যক্তিদের পুর্নবাসনের পরে তাদের বাসস্থান পরিবর্তনের কারন।"

গবেষক: আইরিন সুলতানা, বি.এস.সি ইন অকুপেশনাল থেরাপি (৪র্থ বর্ষ), সেশন ২০১৬- ১৭ ইং, বাংলাদেশ হেলথ প্রফেশনস্ ইনস্টিটিউট (বিএইচপিআই), সাভার, ঢাকা- ১৩৪৩। গবেষনার স্থান: পক্ষাঘাতগ্রস্তদের পুর্নবাসন কেন্দ্র (সিআরপি)- এর নিকটে, সাভার, ঢাকা- ১৩৪৩। পর্ব ১: তথ্যপত্র

## ভূমিকাঃ

আমি আইরিন সুলতানা, বিএইচপিআই-এ বি.এস.সি ইন অকুপেশনাল থেরাপির ৪র্থ বর্ষের একজন ছাত্রী। আমার শিক্ষাকার্যক্রমটি সম্পন্ন করার লক্ষ্যে একটি গবেষনা প্রকল্প পরিচালনা করা বাধ্যতামূলক।এই তথ্যপত্রের মাধ্যমে গবেষনা প্রকল্পটির উদ্দেশ্য, উপাত্ত সংগ্রহের প্রণালী ও গবেষণাটির সাথে সংশ্লিষ্ট নৈতিক বিষয় কিভাবে রক্ষিত হবে তা বিস্তারিত ভাবে আপনার কাছে উপস্থাপন করা হবে।সেই তথ্যপত্রে বর্ণিত তথ্যাদি আপনাকে গবেষণায় অংশগ্রহনের সিদ্ধান্ত নিতে সহায়তা করবে।এছাড়াও,যদি কোন বিষয় বস্তু বুঝতে সমস্যা হয় অথবা যদি কোন কিছু সম্পর্কে আরো বেশি জানার প্রয়োজন হয়,তবে নির্দ্বিধায় আপনি গবেষক এবং এই গবেষণার তত্বাবধায়ক মোঃ মোহসিউর রহমান (প্রভাষক,বিএইচপিআই) এর সাথে যোগাযোগ করতে পারেন।

গবেষণার লক্ষ্য: এই গবেষণাটির উদ্দেশ্য হচ্ছে- মেরুদণ্ডের আঘাতপ্রাপ্ত ব্যক্তিদের পুর্নবাসনের পরে তাদের বাসস্থান সিআরপি-এর আশেপাশে পরিবর্তনের কারন অনুসন্ধান করা । এই গবেষনায় অংশগ্রহনকারী হিসেবে সম্মতিপত্রে আপনাকে স্বাক্ষর করতে হবে। আপনি অংশ গ্রহন নিশ্চিত করলে, আমি আপনাকে কিছু ব্যক্তিগত এবং আমার গবেষণা বিষয়ক প্রশ্ন গুলা জিজ্ঞেস করব। অংশগ্রহনের সুবিধা ও ঝুঁকিসমূহ কি?

গবেষনা প্রকল্পটিতে অংশগ্রনের জন্য,আপনি সরাসরি কোন আর্থিক বা অন্যান্য সুবিধা পাবেন না।এছাড়া এই গবেষনায় অংশগ্রহনের কারনে কোন ধরনের শারীরিক ও মানসিক ঝুঁকি,বিপত্তি অথবা অস্বস্তির মধ্যে পড়তে হবেনা।

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## তথ্যের গোপনিয়তা কি নিশ্চিত থাকবে?

এই সম্মতিপত্রে স্বাক্ষর করার মধ্য দিয়ে আপনি এই গবেষনা প্রকল্পে অধ্যয়নরত গবেষনা কর্মীকে আপনার ব্যাক্তিগত তথ্য সংগ্রহ ও ব্যবহার করার অনুমতি দিয়েছেন। এই গবেষনা প্রকল্পের জন্য সংগৃহীত যে কোন তথ্য, যা আপনাকে সনাক্ত করতে পারে তা গোপনীয় থাকবে। আপনার সম্পর্কে সংগৃহীত তথ্যসমূহ সাংকেতিক উপায়ে উল্লেখ থাকবে। শুধুমাত্র এর সাথে সরাসরি সংশ্লিষ্ট গবেষক ও তার তত্ত্বাবধায়ক এই তথ্যসমূহে প্রবেশাধিকার পাবেন। সাংকেতিক উপায়ে চিহ্নিত উপাত্ত সমূহ পরবর্তী উপাত্ত বিশ্লেষনের কাজে ব্যবহৃত হবে।প্রত্যাশা করা হচ্ছে যে, এই গবেষণা প্রকল্পের ফলাফল বিভিন্ন ফোরামে প্রকাশিত এবং উপস্থাপিত হবে। যে কোন ধরনের প্রকাশনা ও উপস্থাপনার ক্ষেত্রে তথ্যসমূহ এমন ভাবে সরবরাহ করা হবে, যেন আপনার সম্মতি ছাড়া আপনাকে কোন ভাবেই সনাক্ত করা না যায়। তথ্য উপাত্ত প্রাথমিক ভাবে কাগজপত্র সংগ্রহ করা হবে । বিএইচপিআই এর অকুপেশনাল থেরাপি বিভাগে ব্যক্তিগত সমূহ একটি নির্দিষ্ট সময় পর্যন্ত সংরক্ষিত থাকবে। সময় শেষে সেগুলো যথাযথ

প্রক্রিয়ায় ধংস করে দেওয়া হবে

## পর্ব: ০২ সম্মতি পত্র

~মেরুদণ্ডের আঘাতপ্রাপ্ত ব্যক্তিদের পুর্নবাসনের পরে তাদের বাসস্থান পরিবর্তনের কারন"- শীর্ষক গবেষনায় অংশ গ্রহনের জন্য আমাকে আমন্ত্রন জানানো হয়েছে। আমি পূর্বোল্লিখিত তথ্যপত্রটি পড়েছি বা এটা আমাকে পড়িয়ে শোনানো হয়েছে। এই বিষয়ে আমার প্রশ্ন জিজ্ঞাসা করার সুযোগ ছিল এবং যে কোন প্রশ্নের আমি সন্তোষ জনক উত্তরও পেয়েছি। এই গবেষনায় একজন অংশ গ্রহনকারী হবার জন্য আমি স্বেচ্ছায় সম্মতি দিচ্ছি।

অংশগ্রহনকারীর নামঃ

অংশগ্রহনকারীর স্বাক্ষরঃ দিন/মাস/বছর তারিখঃ.....

যদি নিরক্ষর হয়\*

আমি নিশ্চিত করছি যে, সম্মতিপত্রটি আমার সামনে সঠিকভাবে পড়া হয়েছে এবং গবেষণা সম্পর্কে আমাকে প্রশ্ন করার সুযোগ দেয়া হয়েছে। আমি এই গবেষণায় সেচ্ছায় অংশগ্রহন করছি।

অংশগ্রহনকারীর আঙ্গুলের ছাপ:

স্বাক্ষীর নামঃ

স্বাক্ষীর স্বাক্ষরঃ দিন/মাস/বছর

গবেষকের নাম ঃ আইরিন সুলতানা গবেষক স্বাক্ষরঃ দিন/মাস/বছর তারিখঃ.....

তারিখঃ.....

## **Appendix C: Interview question**

## **Interview question**

Date: Code:

**1**.Tell me the details about yourself.

- What is your job?
- Who is in the family?
- What do you like to do?
- -What skills do you have?
- **2.** Explain the time before and after your accident.
- What did you do before?
- -What do you do now? (Source of income)
- -Tell us about a normal day, past and present.
- -How did you spend your leisure time?
- And how do you spend it now?
- Where did you get the treatment?
- **3.**Tell the details about your residence.
- Have you been here since the beginning?

If not,

- -So where were you before?
- -Tell me about the former residence.
- -When did you think you would change your residence?
- -Why did you think?

- Where do you live now?

-Tell me about accommodation here.

**4.** Since the rehabilitation is over, what are the advantages and disadvantages of staying here? Since the accommodation is here!

- What were the advantages and disadvantages of the previous place?

5.Tell me details about your friends or colleagues.

- How was your relationship with previous friends?

-Do they communicate?

-How are your friends or colleagues here?

6. How was your journey to rehabilitation?

-What are your plans for the future at this moment?

-What do you think makes you feel good?

-How confident are you in making the plan a success?

7. Do you have anything else to say?

8. Do you have any comments or sayings about other people like you?

# সাক্ষাৎকার বিষ<u>য়ক প্রশ</u>

# তারিখঃ

কোডঃ

১.আপনি নিজের সম্পর্কে বিস্তারিত বলুন।

-আপনার পেশা কি?

-পরিবারে কে কে আছে?

-কি করতে ভালো লাগে?

-আপনার কি কি পারদর্শিতা আছে?

২. আপনার দূর্ঘটনার পূর্ববর্তী ও পরবর্তী সময় সম্পর্কে বিস্তারিত বলুন।

- আগে কি করতেন?(আয়ের উৎস)

-পূর্বের এবং এখনকার একটি সাধারন দিন সম্পর্কে বলুন।

-অবসর কিভাবে কাটাতেন?আর এখন কিভাবে কাটান?

-চিকিৎসা কোথায় কোথায় নিয়েছেন?

৩.আপনার বাসস্থান সম্পর্কে বিস্তারিত বলুন। -আপনি কি প্রথম থেকেই এখানে থাকেন? যদি না থাকেন,

-তাহলে আগে কোথায় ছিলেন?

-পূর্বের বাসস্থান এর সম্পর্কে বলুন।

-কখন ভাবলেন বাসস্থান পরিবর্তন করবেন?

-কেন ভাবলেন?

- আপনি এখন কোথায় বসবাস করেন?

-এখানকার বাসস্থান সম্পর্কে বলুন।

৪.পূনর্বাসন যেহেতু শেষ, তবুও এখানে থাকার সুবিধা অসুবিধা গুলো যদি বলতেন?যেহেতু বাসস্থান এখানেই! -আগের জায়গায় সুবিধা অসুবিধা গুলো কি ছিলো?

৫.আপনার বন্ধু বা সহকর্মীদের সম্পর্কে বিস্তারিত বলুন। - আগের বন্ধুদের সাথে সম্পর্ক কেমন ছিল? -যোগাযোগ করে তারা? -এখানকার বন্ধু বা সহকর্মীরা কেমন?

৬.পুনর্বাসন অবধি আপনার যাত্রা কেমন ছিলো? -এই মুহুর্তে ভবিষ্যৎ দিন গুলোর পরিকল্পনা কি?

-কি করলে মনে হবে যে আপনি ভালো আছেন/ থাকবেন? -পরিকল্পনা সফল করার জন্য আপনি কতো আত্মবিস্বাসী?

৮.আপনার মতো আরও যারা আছেন, তাদের সম্পর্কে আপনার কোন মন্তব্য বা কিছু

৭.আপনার কি আর কিছু বলার আছে?

বলার আছে কিনা।