SOCIAL EXPERIENCE OF MEN WITH PARAPLEGIC SPINAL CORD INJURY IN BANGLADESH

By

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Statement of Authorship

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The ethical issues of the study have been strictly considered and protected. In the case of dissemination the finding of this project for future publication, research supervisor will highly concern and it will be duly acknowledged as an undergraduate thesis.

Signature _ **Date** _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _

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Abstract

Background: Spinal cord injury (SCI) is a medically complicated and life-disrupting condition. It is a traumatic event which creates many dysfunctions in an individual’s life. Thus, an individual’s engagement and participation in activities can become limited after injury and may need extra support for participating in activities due to their disability that they may not get properly. So they become ignored as being persons with SCI.

Objectives of the study: The objectives were identify the patient’s difficulties of their present social situation in the community, to find out the status of social participation before and after SCI, to find out the attitude of community people towards SCI and to find out the ways to improve the quality of participation in the community.

Methodology: The study was a phenomenological qualitative research design to collect in-depth information from participants. Purposive sampling was used and ten (10) participants who met the inclusion criteria were selected. A semi-structured question, face to face interview was conducted to collect the data.

Result and Discussion: From the finding of the research, it was seen that persons with SCI seem to face various problems such as accessibility problem, negative outlook, lack of support, family separation, avoidance behavior and poor urban planning for the SCI in the society that causes participants sometimes withdraw from social involvement. These factors causing mental distress leads to failure achieve participation in activities and lead an independent life.

Conclusion: Proper rehabilitation service (including awareness, education, and encouragement), family member, and community people supports can facilitate them to cope and overcome these obstacles as much as possible. It also makes sure the successful community participation that ensures individuals are able to generalize their learning across a range of different environments.

Keyword: *Spinal Cord Injury, Paraplegia, Social experience, Bangladesh.*

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List of Acronyms

CBR: Community Based Rehabilitation
CRP: Centre for the Rehabilitation of the Paralyzed
HI: Handicap International
MDT: Multidisciplinary Team
NFOWD: National Forum of Organizations Working with Disability
NGO: Non-Governmental organization
OT: Occupational Therapy
OTs: Occupational Therapists
QCA: Qualitative content analysis
QOL: Quality of life
SCI: Spinal cord injury
WHO: World Health Organization

CHAPTER 1
INTRODUCTION

People with disabilities represent approximately 15% of the world's population (WHO, 2015). Handicap International (HI) and National Forum of Organizations Working with Disability (NFOWD) estimated in 2005 that the percentage of persons with disability is 5.6% of the total population of Bangladesh (Ali, 2013). There are many people living with disability in Bangladesh, but among them, there are a large number of people with spinal cord injury (SCI). SCI is a traumatic life event that results in disturbances in functions and ultimately impacts on the person's psychological and social well-being. It brings sudden and profound life changes (Kalyani, Dassanayake, & Senarath, 2015). Worldwide, huge numbers of people are experiencing SCI every year. According to a WHO report, 20-40 people per million of the population acquire spinal injury every year. In Bangladesh, few studies have been conducted regarding the prevalence of SCI. But the nearest country within Asia is India and there are reported to be 236 people per million of the population who develop traumatic SCI every year (Furlan, Krassioukov, Miller, & Trenaman, 2014). The persons with SCI face major challenges in their social participation, occupational role, preferred lifestyle, and expression of sexuality and in many other areas (Ashekin, 2013). It has a negative influence on the quality of life (QOL) of persons with SCI because it leads to a high level of long-term disability, morbidity, mortality and causes an overall economic burden on a family, society, and country (Razzak, Helal, & Nuri, 2011). Persons with SCI have many experiences during participating in social activities. In community activities, long-term social experience may decrease or improve the person's involvement in the society. These changes have profound effects on a human social role and social relationships among their community members. The survival of men with paraplegic SCI population is very high in the community (Bickenbach et al., 2012), even after completing the goals of rehabilitation service. There are lots of factors in our community life relating to reduced life expectancy.

It is seen that in the Bangladeshi community, most of the persons with SCI want to engage in social activities (Brown, Gordon, Spielman & Haddad, 2002). During community participation persons with SCI try to participate in social activities as much as possible, but they may need extra support for participating in activities due to their disability that they may not get properly. That's why the community people feel that they are useless in the community and become ignored as being persons with SCI. So, persons with SCI become upset and get isolated from society. When they are not participating in activities, their QOL may decrease. Therefore, they cannot engage properly in the society. From the Bangladeshi perspective, it is an important issue to conduct this study because it will be helpful to explore the social experience of the men with paraplegic SCI in Bangladesh.

1.1. Background

Spinal cord injury (SCI) is a medically complicated and life-disrupting condition (Krug, 2013). It is a traumatic event that often occurs unexpectedly. The effects are immediate which creates many dysfunctions in an individual’s life. An individual’s engagement and participation in activities can become limited, so the persons with SCI become socially isolated. Many persons with SCI face challenges regarding their physical, psychological and social functioning (Singh, Rohilla, Swach, Dhankar, & Kaur, 2012). It is a common problem of the health sector all over the world but the incidence varies from country to country. SCI is one of the major public health problems in Bangladesh (Hoque, Hasan, Razzak, & Helal, 2012). There is no governmental rehabilitation center for persons with SCI in Bangladesh. There is only one Non-Governmental Organization (NGO) is The Center for the Rehabilitation of the Paralysed (CRP) that works for persons with SCI in Bangladesh. It is one of the renowned rehabilitation centers for the paralyzed; the majority of people with SCI in Bangladesh are treated from this rehabilitation center. It represents the whole SCI population of Bangladesh. An epidemiological study of CRP showed that both tetraplegic and paraplegic patients get admitted here. Among them 79.75% were paraplegic and 20.25% were tetraplegic and the male and female ratio was 91.14% and 8.86% (Razzak et al., 2011). The last annual report of CRP showed that from 2013-2014, 388 patient were admitted with SCI of whom 88.4% were male and 11.6% were female (Annual Report of CRP, 2015). During treatment in this setting, persons with SCI completed acute, active, rehabilitative and community reintegration phases. In community reintegration phase family members and community, people work as a key person for adjusting them to new situations (Emerich, Parsons, & Stein, 2012). After completing these phases, persons with SCI return to the society.

Participating in social activities after SCI is an ongoing process that is influenced not only by rehabilitation but also its dependence on personal attributes, family and social support, availability of housing, transportation and other characteristics of the environment (Bickenbach et al, 2012). Social participation means that individuals are involved in activities and social programs (Wandell, 2010). SCI causes limitation and disruption of adjustment, personal choice, socioeconomic circumstances, financial stability and social support. For these reasons their lifestyle changes. Proper rehabilitation and various helping hands may help them to lead their life well and to perform activities in a meaningful way.

Persons with SCI generally might need help in performing social activities but they do not get support when participating in activities, so they may experience a debilitating psychological impact. 20–30% of people with SCI show clinically significant symptoms of depression that are greater than the overall general population (Bickenbach et al., 2012). Additionally, persons with SCI suffer from anxiety, they think of themselves as a neglected person and they do not want to receive help from their relatives (Kennedy, Duff, Evans, & Beedie, 2003). Sometimes this thinking creates an unwanted situation for the person with SCI. In addition, persons with SCI always feel insecurity about the upcoming situation. Men are the key earning person in the Bangladeshi family so they are likely to feel worry about the maintenance of the family's income. That's why the author will investigate common social experiences of persons with SCI from the point of view of men with paraplegic SCI.
Persons with paraplegic SCI may face difficulty to participate in social activities for a short period of time after returning to their community even though they have completed the rehabilitation. Therapists, family members, and community people are in prime concern of regarding Persons with paraplegic SCI to ensure their QOL. The literature showed that as a developing country there are limited rehabilitation services for persons with SCI (Ning, Qiang, Yu-Lin, & Feng, 2012). So they are not enabling to survive in the community as a result of a limited preventable factor. For this reason, they are not able to actively participating in the social activity after returning the community though they live in their own society (Williams, 2015). There are some studies addressing QOL, mortality, survival of the SCI population. But there are hardly any available explorative studies concerning the social experiences of men

with paraplegic SCI in Bangladesh. It is important to find the specific factors that affect Bangladeshi communities and explore these issues.

1.2. Significance

Persons with SCI face difficulties within the community including personal, environmental, attitudinal, cultural and social difficulties. Typically, a person with SCI is treated as a burden on society. People in society sometimes mistreat them. For these reasons, they need to deal with things to survive.

Different people follow different coping strategies in the community. There is not enough study to explore the social experiences of the persons with SCI. The investigator will find out the social experience and cope strategies among men with paraplegia. Therefore, it is very important to find out how people in the community view disability.

The aim is for persons with SCI to become aware of their community barriers such as personal, environmental, social and attitudinal barriers. They will then be able to cope with the situation by practicing coping strategies. They would not be discriminated in the community as a person with SCI. They will get better opportunities for participation in the community and they will be able to successfully integrate into the community.

Occupational therapists work with SCI from the acute phase to the community reintegration phase (Ferdous, 2015). They also work towards accessibility, social participation, positive thinking and home exercise (Fristedt, 2012). Training in socialization skills is an integral part of community reintegration. Using the results from this research, occupational therapists will work with the persons with SCI to improve their ability to perform in the society as independently as possible. As an occupational therapist, our aim for persons with SCI is to improve the quality of life in their society through reintegration. In most cases, people with SCI are unable to return to their previous occupation and need to learn new skills in order to cope with the difficulties in their society. This research will help new occupational therapists to modify, redesign and develop the occupational therapy service in the SCI setting. This will be beneficial for the clients and for the occupational therapy profession. Thus, the goal of OT will be more realistic, which will ultimately lead to the benefit of patients.

The OTs and the students of occupational therapy will be able to enrich their knowledge and resources by using this research study in Bangladesh. They will also establish different management strategies for the persons with SCI in their community.

In the community reintegration phase, different professionals are working as part of a multidisciplinary team (MDT). In the MDT, many professionals work together such as Occupational therapists, physiotherapists, community-based rehabilitation (CBR), social welfare, social worker and more. Other professionals can work with the persons with SCI to reduce barriers by increasing awareness among society. They can also work to improve QOL of persons with SCI.

1.3. Aim

The aim of the study is to explore the social experience of men with paraplegic Spinal Cord Injury in Bangladesh.

1.4. Objectives

- To identify the patient’s difficulties of their present social situation in the community.
- To find out the status of social participation before and after SCI.
- To find out the attitude of community people towards SCI.
- To find out the ways to improve the quality of participation in the community.

CHAPTER 2
LITERATURE REVIEW

SCI is a traumatic injury that typically happens suddenly and unexpectedly. The results of SCI have a vast effect on many parts of a person's life that results in massive changes in an individual's lifestyle. Paralysis leads to wheelchair dependency and persons with SCI needs help during social activities, social participation, community access and recreational activities. Moreover, because the individual has physical and psychosocial limitations, it may be stressful. Stress is caused by the difficulty in adjusting to a new situation. It creates great problems for the affected individual's previous role in society (Babamohamadi, Negarandeh, & Nayeri, 2011). All of those issues create tremendous challenges in adapting to social aspects as well as to the living situation, relationships, and adjustments. The person with SCI primarily faces problems when returning to their previous community setting. Rehabilitation will promote full inclusion and participation of persons with SCI within the physical and social setting. Rehabilitation of the person with SCI focuses on engagement in productive community reintegration by overcoming close environmental and social barriers created for SCI.

2.1. Spinal cord

The spinal cord is the main pathway of communication between the brain and the rest of the body. The spinal cord is cylindrical in shape and slightly flattened in the anterior and posterior areas (Back, 2006). It is a long, fragile and tube-like structure that extends downward from the base of the brain. The cord is protected by back bones (vertebrae) of the spine (spinal column). The vertebral bodies protect the spinal cord anteriorly and the vertebral arches protect it laterally and posteriorly. The spinal cord is the major canal through which motor and sensory information travels between the brain and body (Kirshblum et al, 2011). Traumatic or non-traumatic injury in the spinal cord may cause disruption in the body's communication, thus resulting in a loss of function.

2.2. Spinal cord injury

Spinal cord injury usually happens due to a sudden, traumatic injury to the spine. This injury or damage leads to fracture or dislocation of the vertebrae or intervertebral discs which in turn ruptures the spinal cord partially or fully. According to

Apparelyzed spinal cord (2015), a spinal cord injury is defined as injury or trauma to the spinal cord that in turn leads to reduced mobility or feeling.

SCI results from an accident that breaks or severely damages the spinal cord within the segments of the neck and back. Persons with SCI must change their daily living activities after injury. They also have to adjust to the society and each individual who related in their personal life. Thus social participation is a very important issue to deal with society member for persons with SCI after injury.

2.3. Incidence and prevalence of SCI in Bangladesh

Spinal cord injury can be traumatic or non-traumatic. The common causes of SCI in Bangladesh are falls while carrying a heavy load on one’s head, road traffic accidents, falling from a height, fall of a heavy object on the head or neck, bull attack, and diving into shallow water but most of the SCI are occurred by accidental falls while carrying a heavy load (Razzak et al., 2011). During harvest season, the farmers and laborers carry their product on their head and transport them from gathering areas to store room or from one place to another place. According to the WHO, worldwide between 20-40 individuals per million of population acquire spinal injury every year (Hasan et al., 2009). In Bangladesh, most SCI occurs between the ages of 26 and 35 and 86.7% of them are male (Akter, 2014).

2.4. Persons with SCI

Injury in the spinal cord affects sensory and motor signals across the site of lesion, as well because the autonomic system (Kirshblum et al, 2011). There are complete and incomplete injuries in spinal cord injury. According to American spinal cord Injury Association (ASIA) 2000, complete injury consists of the absence of sensory or motor function within the lowest sacral segment (S4-S5). The spinal cord is broken totally through compression, dislocation, rotation, extension, overstretching or a complete disruption of the blood supply. A complete injury means the patient has no sensation or movement below the lesion. If the gray matter of the spinal cord dies then the injury is irreversible. The term incomplete injury is used when there is the partial preservation of sensory and/or motor function below the neurological level and in the lower sacral segment (S4-S5). Men with paraplegia have the capability to lead a more independent life by using the upper body.

2.5. Persons with paraplegia

According to the spinal cord injury zone (2005), Paraplegia is the loss of sensation and movement in the legs and partially in the trunk, sometimes resulting from an injury to the spinal cord below the neck. Paraplegia refers to the loss of sensory and motor function within the thoracic, lumbar or sacral segments of the spinal cord. Paraplegic function depends on the level of injury; the trunk, legs, and pelvic organs could also be affected (Kirshblum et al., 2011).

Paraplegia can be divided into two levels: high paraplegia and low paraplegia. High paraplegia is referred to the spinal cord T2-T6 and low paraplegia refers to T7 and below (Somers, 1992). The functional level of the person with paraplegia depends mainly upon the level of the injury. For men with paraplegia upper body strength is preserved and they have greater independence than men with tetraplegia in all aspects of their lives. From a Bangladeshi perspective, men with paraplegia have the capability to lead a largely independent life, participate in social activities and engage in employment, depending on their circumstances.

2.6. Situation of SCI in Bangladesh

Bangladesh is one of the world's most densely populated countries and its social facilities are developing day by day. The population of Bangladesh is estimated at 160,411,249 (Worldometers population, 2015). Most of the Bangladeshi population lives in rural areas (Ahmmad & Islam, 2014). SCI is a very important issue in Bangladesh (Hossain et al., 2011) and a person with SCI is treated as a person with a disability. People with disabilities may get the opportunity to access support services in the employment, academic and social sectors but the facilities are not yet widespread across the country due to ignorance, illiteracy, low socioeconomic conditions and poor infrastructure (Haque, Grangeon & Reed, 2011). Some non-government organizations work to rehabilitate people with SCI. Additionally, there is awareness raising programs conducted by different organizations at the community level (Titumir & Hossain, 2005). People with SCI face problems in participating in functional activities such as weddings, daily life, academic roles, and employment because of their disability. Some literature shows that most people in the community look negatively towards people with SCI. They also face a lot of negative reactions and some psychological complications due to misguided beliefs about SCI. For example, in the Bangladeshi community, many people believe that SCI is the result of a curse (Hossain et al., 2002).

People in the community have a lack of knowledge about SCI. Most of the specialized hospitals and rehabilitation centers are located in urban areas. Most of the time rural people cannot reach acute care facilities after SCI because of the long distance to the hospital (Gert, Pempelani, & Elina, 2015). There are only a few rehabilitation centers in Bangladesh that help a person with SCI to lead a better standard of life after SCI. The hospital at CRP, Savar is the only hospital in Bangladesh that has specialized treatment for SCI patients (Annual report of CRP, 2015). CRP provides four phases of treatment, including community reintegration which is considered necessary for a person with SCI (Annual report of CRP, 2015). After completing the reintegration phase, most of the persons with SCI are discharged from a rehabilitation center to resume their social life roles.

2.7. Community

The community is an important context that influences people's ability to engage in occupations. Communities are not simply defined by geographic location but refer to a person's natural environment that is, where the person works, plays and performs other daily activities (Doll, 2010). Communities can facilitate or inhibit occupational engagement of those with or without SCI. Persons with SCI have the ability to engage in maintenance activities but demonstrates simple barriers to performing and well-being in the community. Community characteristics (including socioeconomic status, culture, political infrastructure, public transportation, availability of healthcare services and geographic location) affect community health status. Each community belongs with totally different society, culture, people, and setting. So the social environment may result in discrimination or difficulties for the person with SCI.

2.8. Social Environment

Social environment influences the natural environment. It describes the environment that developed by humans and it has a relationship with the individual. The social environment has a clear and profound impact on health and wellbeing of humans and other social mammals. Environmental factors affect large groups of people that share common living or working spaces. The factors may play an important role in social participation and as part of a reinforcing cycle for participation within the community.

Environmental factors and community level factors reinforce each other over time and play a crucial role for participation in the society.

Social support has been identified in a large number of studies of the SCI population as a variable that is important to facilitate a positive outcome (Fatih et al., 2007). Persons with SCI may experience financial, social and economic deprivation because the social environment in Bangladesh is not adapted for them (CRP-Bangladesh, n.d.). It has been found that an individual who has a high level of social support and is satisfied with the quality of social contacts reports a greater sense of well-being (Müller, Peter, Cieza, & Geyh, 2012). Persons with SCI are relatively inactive and likely to have lost their occupation. They may be dependent on others, so the quality of life may also be affected. By all of these processes the person may be affected psychologically leading to psychological problems. If this psychological burden is excessive it may lead to an emotional breakdown for the persons with SCI (Manigandan et al., 2000).

2.9. Social Participation

According to the constitution of Bangladesh (2013), all citizens have the right in society to enjoy their dignity, fundamental human rights and have social equality and social participation. It refers to people's social involvement and interaction with others in the community. Social participation are those activities undertaken in and outside of the house, that enables the individual to meet with others, contribute to society and stay involved in society (Aartsen, 2015). Activities like jobs, business, sports, and recreational activities are all forms of social participation. Frequent social participation was classified as an at least weekly family or friendly relationship activities outside the family, church or religious activities like services, committees or choirs, sports or physical activities with others, and alternative recreational activities involving others, including hobbies, alternative games (Gilmour, 2015). The full participation of persons with SCI benefits society as their individual contributions enrich all spheres of life. Their participation is an integral part of individuals' and society's well-being and will benefit society for all with or without disabilities (Human right and person with disability, 2007). The law has referred to barrier-free movements for persons with SCI. This includes equal access to all social activities/services such as infrastructure, communication, transportation, information, and technology. Persons with SCI are not completely engaged in activities due to the situation in Bangladesh.

2.10. Attitude towards persons with SCI in Bangladesh

Persons with SCI are seldom addressed by their actual names and instead they are called by their disability in its rudest and cruelest interpretation. They are also excluded from social programs, community activities, entertainment, games, collective events etc. They have been either refused or discouraged in gaining access to any recreational events like cinemas, theaters, parks etc. These people have in fact been left out of the process of social interaction and mainstream development (Islam, 2004).

The World Bank estimates that disabled people make up 15-20% of the poor in developing countries. Poverty has been considered a major factor such as situation. But at the same time the different attitudes and sentiments of the people in families and in communities, also have immense influences in creating such handicapping environments (Islam, 2004). So, most people with SCI suffer from frustration and have an inferiority complex because of their limitation.

There is an attitude of neglect regarding their job, social activities, schooling, food and clothing which may be shared unequally. They are also isolated from participating in recreational and entertainment events (Islam, 2004). So, social change is needed on many levels to create real change. On the other hand, attitudinal changes of the community are one of these changes that will improve the participation SCI people and their access to equal rights in society.

CHAPTER 3
METHODOLOGY

3.1. Study design

The study was phenomenological qualitative research design that was descriptive, exploratory and contextual to identify the experience of persons with paraplegia SCI about their social experiences in the community. The phenomenological qualitative study design was selected because this method helps to explore the in-depth information on the experience of the participants (Bailey, 1997). Hicks (1999) said that "*Qualitative research is exploratory in nature by which the researcher can gain insights into another person's views, opinions, feelings, and beliefs, within their own natural settings."* For this reason, qualitative research design was selected to identify participant's perceptions, views, and experiences in this study.

The aim of the study was to explore the social experience of the men with paraplegic spinal cord injury in Bangladesh. A qualitative design and semi-structured face to face interviews were selected to identify the social experience in the community. By semi-structured interview, participants obtained autonomy to explain their opinion, to share knowledge from their own point of view.

3.2. Sampling

The aim of the study was to explore the social experience of the men with paraplegic Spinal Cord Injury in Bangladesh. Subjects were collected by using purposive sampling from the population who met all inclusion criterions. Purposive sampling was used because the investigator could not find out whoever was available, but could use judgment to select a sample (Mamo, 2015). This method also used to find out the live experience of a specific population. Samples were selected from different community settings and persons with paraplegia who lived in the community. It is one of the most common types of non-probability sampling to complete the study within the fixed time period. The investigator selected purposive sampling procedure for the study as this procedure can be conducted relatively easily and with minimal financial costs. So participants were selected by purposive sampling for conducting the study.

In qualitative studies the sample size becomes generally very small (Bailey, 1997) and the subjects were selected because of some characteristic. According to Thumb Based on Approach, 10 people were selected for this study as it was a phenomenological qualitative study (Nastasi, n.d.).

3.3. Inclusion criteria

- Participants were selected from 18 to 65 years of men with paraplegic SCI. Because in these age ranges most of the person involve in social activity. People of above 65 ages may face physical and psychological problems. For this reason, their participation becomes restricted.
- Men with paraplegic SCI who completed rehabilitation program from CRP.
- Persons who stay in the community for more than 3 months after completing reintegration phase.
- Participants were selected who use any assistive device like wheelchair, crutches, walking frame or stick.

3.4. Exclusion criteria

- Persons who have hearing impairment & speech problem or having any sort of cognitive problem.

3.5. Study setting

In the study data was collected from Dhaka Division including Dhamrai, Manikganj, and Savar Thana, persons with paraplegic SCI who live in the community. It was easy to gather information from persons with SCI who are treated and completed rehabilitation program from CRP.

3.6. Informed consent

In the study used an information sheet and consent form both in English and Bengali. Here used the Bangla consent form during the interview. The participants informed about details of the study by the information sheet which included the aim, objectives, way of collecting data from the participant and the ethical considerations of the study. There also be used the consent form containing the consent of the participant that they would like to participate in the study and gave permission to start the data collection sessions.

3.7. Field test

Two participants who returned to the community after completing treatment from CRP were informed about the aim and objectives of the study during an interview session at first. Here one participant’s education level was SSC and another person was primary school pass. It was important to carry out a field test before collecting the final data as it was helpful for the investigator to refine the data collection plan. This test was performing to identify any difficulties. The first participant had difficulty to understand questions then the investigator was rewrote the question to make it clearer, and easy to understand for the participants.

3.8. Ethical considerations

Ethical consideration is important to avoid the ethical problem. The study needed to maintain some ethical considerations. Proper ethical consideration tells about the transparency of any work which is mandatory to avoid conflicts. So, to keep the accountability and transparency of the work, it required maintaining some ethical considerations from the first phase of the study.

- Permission was taken from the supervisor and course coordinator of Department of Occupational Therapy, Bangladesh Health Professions Institute (BHPI) which was the academic institute of CRP to conduct the study.
- Permission for data collection was acquired from Rehabilitation Wing of CRP.
- The participants were informed of the participation in the study. A written consent form was used to take the permission of each participant for the study.
- All participants were ensured that they were informed about the aim and objectives of the study.
- It was ensured that the organization (CRP) was not hampered by the study.
- All kinds of confidentiality were highly ensured.
- Participants were also informed that their information might be published but their name and address would not be used in any way in the research project to maintain confidentiality.
- It was committed that information never being shared with others that were given by the participants except the research supervisor.
- These materials disposed of after completion of the research project.

- Recorded data, written data, transcript destroyed after six months following the study.
- Participants also informed that they would not be benefited/ harmed due to being a participant in the study.

3.9. Materials of data collection

The study used a self-structured questionnaire and a tape recorder to record the interview with all of the participants during interview time. The audio recording was necessary to develop full transcripts of the interview, which should be accessible to independent analysis (Lowrance, 2006) because it was very difficult for an investigator to write every question answer in details during the interview. The consent form was used for taking permission from the participants. Otherwise pen, pencil, white paper, clipboard were also used to collect the data.

3.10. Data collection procedure

To collect data from the participant the study used semi-structure self-developed questionnaire with face to face interview. Bailey (1997) states that ‘interview conduct face to face is more invite allowing the interviewer to interact directly and develop a rapport with the interviewee’. The study used the qualitative methodology and asked pre-set, open-ended questions addressing a variety of issues in relation to finding out the experiences. It was useful because this technique ensured that here obtained all information required while at the same time gave the participants freedom to respond and illustrate concepts.

At first, it was required to address the subjects and informed participants of the study. Then the opinions of subjects also took who are interested and confirmed time and date of the interview. Then a quiet place was selected where participants felt comfort and abled to give adequate attention during the interview. It was ensured that nobody would present during the interview time at the interview place. At first consent form was taken from the participant and investigator spends some time to build rapport with the participants. The aim of the study explained to take the consent of the participants by the investigator. Consent was a very important element during an interview, because if the participants felt uneasy to discuss sensitive issues then they might hide the truth. The questionnaire was based on to explore the social experience of the men with paraplegic SCI in Bangladesh. The interview was conducted in

Bengali so that participants would be able to understand easily. The answer was recorded by a tape recorder. The notes were written by the investigator. Time range was approximately 25-30 minutes for each interview.

3.11. Data analysis

The qualitative content analysis (QCA) method was selected to analyze the data. According to Stemler (2001), 'Content analysis has been defined as a systematic, replicable technique for compressing many words of the text into fewer content categories based on explicit rules of coding'. It facilitated the formation of core data through a systematic method of reduction and analysis. The theme of the study was created by systematic reduction and analysis of data. QCA followed three steps (coding, categorizing and generating theme) to show the result of the study. In a short line, it was said that texts were coded into established categories to support the generation of ideas (Denscombe, 2003).

Qualitative data analysis is a complex process. Content analysis was used to discover themes as it was a common data analysis procedure most often used in qualitative data and based on searching for repeated words, phrases or concepts (Hissong, Lape, & Bailey, 2014). At first, it included systemic organization of the field notes, transcripts of interviews and other associated materials. From this data an understanding of how this addressed the research question was formed. The analysis of the data began with transcription of the interviews. From data analysis, the entire interview in Bangla from a recorder was transcribed by the investigator. The relevant issues related to the study observed and noted it down by the investigator. It was then given to two individuals who were competent in English, with the intention that they could transform it separately from Bangla to English. Then the accuracy of the data was verified by the investigator. It was read several times by the investigator to recognize what the participant wanted to say. The audio tape was also listened by investigator again to ensure the validity of data.

Analysis of the interview data began with content analysis. It involved taking a volume of qualitative material and attempting to identify core consistencies and meanings. Then data was coded into broad categories as dictated by the research question. Then the major themes from each interview were coded during initial category coding. The second stage involved identified information units. Information units were categorized into themes in the identifying experience of persons with SCI. Finally, analysis of interview data began by analyzing text from the categorized data and code themes. At last, the key themes were also analyzed based on the literature.

3.12. Rigor

The study was conducted in a rigorous manner. All of the steps in the research process were supervised by an experienced supervisor. The investigator did not try to influence the process by biases, values or own perspectives during the interview and analysis of data. The investigator was always asked open-ended questions, no leading questions would be asked and the investigator would not interrupt the participants during answering the questions. Similarly during data analysis, the investigator would not submit according to own perspectives. Data were recorded carefully and investigator accepted the answers of the participants whether negative or positive without giving them any impression. The investigator had prepared the transcript from the field notes and audio recording. Then it was written soon after the interview. The initial translation was completed by another two people, then investigator completed the same translation and finally all translations were compared. Investigator checked the translated data several times so that no information was missed. Notes were handled with confidentiality. In the result section, the investigator did not influence the outcome by showing any personal interpretation.

Summary of data analysis and result

Objectives	Questions	Categories	Themes
1. To identify the patient's difficulties of their present social situation in the community.	**1, 2**	**Category 1:** Difficulties are faced in the community after SCI.	Persons with SCI face various types of difficulties like negative outlook, avoidance behavior, and accessible environment after returning in the community for participation in activities that causes participants sometimes self-withdraw from social involvement.
2. To find out the status of social participation before and after SCI.	**3, 4, 5**	**Category 2:** Social activities or programs participated before SCI.	Most of the participants participate in different types of activities like the cultural program, sports, family program, and social program before SCI, but after SCI few of participants cannot participate as before but many of the participants can participate in many activities like social work, business, sports, and social program after SCI.
		Category 3: Social activities or programs participated after SCI.	
		Category 4: Social problems during participating in social activities or programs.	Most of the participants suffer negative attitude or outlook during participating in the social program or activities that cause family member does not allow them to attend any social activities.
3. To find out the attitude of community people towards SCI.	**6, 7, 8**	**Category 5:** Attitudes of the family members, neighbors, and relatives for the current situation.	Most of the participants suffered negative attitude and less than half of participants experienced positive attitude and get support from their family members, neighbors, and relatives.
4. To find out the ways to improve the quality of participation in the community.	**9, 10**	**Category 6:** Strategies to overcome these social problems.	Most of the participants said that society people have to be aware of disability (SCI), their right, capabilities, limitation, and half of the participants claimed that they need social support to overcome these social problems.

CHAPTER 4
RESULT AND DISCUSSION

In this research, result and discussion have been described in same chapter because this is common practice in reporting on qualitative studies. It is found that generally the result and discussion were presented together in one section because this is the general practice in reporting on qualitative studies (Hissong, *et al.*, 2014). The findings and discussion have been presented together with the necessary literature support. Each of the tables below represents the collected data. Each table describes the interview findings. The tick was given only for those columns where the participants expressed their opinion. Here, ‘P’ means participant and P1, P2, P3… means a number of participants.

4.1 Findings at a glance

Theme-1: Persons with SCI faces various types of social problems.

Theme-2: Persons with SCI participated in different types of social activities before and after SCI.

Theme-3: Different types of problems are faced by the persons with SCI during participating social activities.

Theme-4: Persons with SCI have both positive and negative impacts on their relationship with family members, neighbors, and relatives.

Theme-5: There are different ways to overcome the social problems of persons with SCI.

Category 1: Difficulties are faced in community after SCI

Coding	**P1**	**P2**	**P3**	**P4**	**P5**	**P6**	**P7**	**P8**	**P9**	**P10**
Avoidance behavior		√		√				√	√	√
Negative outlook	√		√	√			√	√		√
Prejudice			√							
Myth about disability			√							
Think about acceptance	√						√			
Can't participate in family program		√			√					
Can't participate in Sports		√								
Self-withdrawal	√				√					
Accessible environment	√	√		√	√	√			√	

Table-1: Problems are faced in community after SCI

Most of the participants said that they face accessibility, negative outlook problem, and avoidance behavior. One of the participants said that-

"I can't attend program or activities, they don't help me to attend in activities just for my abnormalities and they try to avoid me."

According to Hosseinigolafshani, Abedi, & Ahmadi (2014), this negative attitude of people has led to distressing behaviors toward the persons with SCI. During interview time, participant states that everyone always tries to avoid me for my disability and they don't help me to attend in social activities.

Another participant said that-

"I can't attend family and social program, when I see there is a positive environment for me only then I attend there, otherwise I avoid it."

Participants in their interview time state that, psychological and physical effects may arise if they did not participate in social activities. It may become a cause for persons with SCI to withdraw from social involvement (Hess & Hough, 2012). As a result, when persons with SCI find that independence in social activities has not been achieved, they sometimes lose their sense of meaning in life and become socially withdrawn.

Another participant also said that-
"There are many problems. I face accessibility problem, and I also face negative outlook, it has changed after my injury."

According to McKinney (2013), after completing the reintegration program persons going to their own community following SCI and they face many barriers in the community like accessible environment problem, negative attitudes towards their disability, inaccessible door, stairs, uneven surface. It is also seen that in Bangladesh structural barriers for persons with SCI include inaccessible environment and inaccessible work and transport systems. The interactions of SCI with the society people and family member have frequently negative effects that have a severe impact on social participation.

So it indicates that maximum participants face various types of difficulties after returning in the community for participation in activities like negative outlook, avoidance behavior, and accessible environment and that causes participants sometimes withdraw from social involvement.

Category 2: Social activities or programs participated before SCI

Coding	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10
Cultural program	√	√			√	√				
Sports		√	√		√	√				√
Family program			√	√	√		√			
Social program			√	√			√		√	
Politics	√									
Social work	√		√							
Farming								√		

Table-2: Different types of social activities or programs participated before SCI

Most of the participants participated in many social programs like the cultural program, sports, social program before SCI. One participant said that-

"All kinds of social, family program, sports, and different social welfare."

Wandell (2010) had shown that persons with SCI participate in different types of physical activity before injury like sports. According to Carpenter, Forwell, Jongbloed, & Backman (2007), they can actively participate in the social programs, such as visiting or going out with family members or friends, participating in the social gathering, physical activities, and social welfare activities. Before the injury, they are key earning member in their family and they participated in social or family program and social welfare activities.

Another participant said that,
"I attend many cultural programs, fair, festivals, sports, and visit outside. I would like to go to any concerts of our society with my friends by riding a bike."

Social participation contributes to the progress of life and has been regarded as an important component of QOL. Participation in social activities and cultural program removes effects of chronic physical and mental problems and it is also very helpful for keeping fit. The literature showed that most of the time they participate in different types of activities before the injury (Martínez et al., 2005). So it is inferred that before SCI most of the participants participate in different activities such as cultural program, sports, family program, and social program.

Category 3: Social activities or programs participated after SCI

Coding	**P1**	**P2**	**P3**	**P4**	**P5**	**P6**	**P7**	**P8**	**P9**	**P10**
Business						√			√	√
Social program				√			√		√	√
Can’t participate as before		√			√			√		
Social work (like- work for PWDs)	√					√				
Participate as before			√							
Sometimes participate							√			
Participate in sports						√				

Table-3: Different types of social activities or programs participated after SCI

From this study, it has found that after SCI nearly half of participants (3 out of 10) couldn’t participate as before but many of the participants engaged in social activities after SCI like social work, business, sports and social program. One of the participants said that,

“I am running my business of my departmental store in my home, attending in any social activities in my local areas.”

Literature shows that persons with SCI tried to get back to their previous role of employment after injury (Kurtaran et al. 2009, p.711-712). So it is possible to increase social adaptation and improve life satisfaction by participation in productive activities like business, employment as well as by training and suitable employment. Another study shows that benefits of participating in social program/activities after SCI include mental satisfaction and improve social contact with others in the community (Schonherr, Groothoff, Mulder, & Eisma, 2005, p.241).

Another participant said that,

"I took training on basketball also play it with power lifting. I feel good when I spend time with my cousin and we pass time on the top of the roof. Even I played badminton. I have a shop in a shopping mall then I work there even I have a Savar disability foundation where I am a member of it and I am also a member of other organization. I do hand work as much as possible."

Among ten participants seven participants could participate as before in the social activities and other three participants could not participate as before. As mentioned by Ginis et al. (2010) that, an individual should engage in physical activities during their free time such as wheeling outside, playing sports, or exercising in a gym. Following the injury, all of them also participated but there was the difference between the pre and post injury participation. Another study revealed that just under half of people with SCI who participated in this study engaged in some sporting activity each week, the majority of whom (78%) preferred individual over team sports but over half of the participants were unable to continue with their favorite sport due to their injury or lack of opportunity and 74.6% indicated that accessing information about sports participation post-SCI was difficult (Tasiemski, Kennedy, Gardner, & Blaikley, 2004).

So it indicates that after SCI few of participants cannot participate as before but many of the participants can participate in social activities after SCI like social work, business, sports and social program.

Category 4: Social problems during participating in social activities or programs

Coding	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10
Negative attitude or outlook			√	√			√	√	√	√
Can’t participate	√				√	√		√		
Lack of family support		√						√		
Feel deprived	√									
Accommodation					√					

Table-4: Many types of social problems during participating in social activities or programs

From this study, it can be shown that during participating in the social program or activities, a large number of participants (6 out of 10) suffered from negative attitude or outlook. More than half of the participants (6 out of 10) said that,

“When I go any program then I face negative attitudes, they always behave like neglect. They think that a disabled person has no right to attend a program. That time I feel uneasy and deprived.”

The literature showed that persons with SCI could not participate in activities after SCI due to accommodation, negative attitudes towards them (Ottomanelli et al., 2012). In this study, nearly half participants (4 out of 10) are deprived and isolated from their social activities and the main reason behind this was the negative attitude of people towards them.

Another participant said that,

“Now I am participating in many social activities but not like before. For example concert, sports, and many kinds of social activities are helding in any place but I cannot go there.”

Babamohamadi, Negarandeh, & Nayeri (2011) stated that one of the main obstacles for persons with SCI is adaptation with their new situation after the injury due to lack of social acceptance and support. As a result, a family member does not allow them to attend any social activities. Another study showed that the number of the SCI affected a person to return to the previous work is very few (Ottomanelli et al., 2012). Persons with SCI need many types of environmental modification for greater adaptation in the home and the society. As a result, their social participation decreases after SCI.

So the study result concludes that after SCI, a large number of participants suffer from negative attitude or outlook during participating in the social program or activities.

Category 5: Attitudes of the family members, neighbors, and relatives for current situation

Coding	**P1**	**P2**	**P3**	**P4**	**P5**	**P6**	**P7**	**P8**	**P9**	**P10**
Negative attitude	√	√	√	√		√	√	√	√	√
Positive attitude	√					√			√	√
Lack of support		√	√					√		
Support others					√		√			√
Family separation				√		√			√	
No change in relationship									√	√
No expectation	√									

Table-5: Different attitudes of the family members, neighbor, and relatives for the current situation

In this study, it is shown that their family members, neighbors, and relatives attitude has changed after injury. Most of the participants suffered negative attitude and less than half of participants experienced positive attitude and get support from them. Maximum participants (9 out of 10) said that,

"All of them had a negative attitude. They thought that we can't do anything, so we are valueless."

Krahe & Altwasser (2006) said that the attitude of society people like negative attitudes towards people with SCI is seen after the injury. Most of the participants wanted to participate in any social and productive activities, which is very important to become a valuable and respected part of the society. Role in the family and society is an essential part of persons with SCI. It is influential in personal relationships and interaction both within and outside of the family. It indicates that most of the participants had complained about their family members, neighbors, and relatives that they had changed their attitude toward them after the injury.

Nearly half of the participants (3 out of 10) said that,

"Their attitude also become changed after my injury, they are not always support me so I need to face many problems."

It is estimated that usually, 40% of all individuals with SCI can get at least some assistance with personal care and over half of these individuals can receive assistance from family members but others cannot get the support (Elliot, Kurylo, & Lindsey, 1998 cited in Phyllis, Ellenbogen, Michelle, Meadea, Njeri, & Kirsten, 2006). That means there is still now lack of support for persons with SCI due to their injury.

Most of the participants said that,

"Their perspective was same. Their family member, neighbors, and relatives thought that they would not able to work. Their family member, neighbors, and relatives also said them (persons with SCI) what should they had done by going outside, but persons with SCI also said that this negative attitude was changed when they engaged in any work."

Harrison, Umbersonn, Lin, & Cheng (2010) also stated that the frequent undesirable interactions have a negative and severely destructive impact on the individual's QOL. Dorsett (2001) also explained in his study that social support has been identified in a large number of studies of SCI populations as a variable that is important in facilitating positive outcomes. All of them mentioned that they could not attend at any social program because their family member did not like to go with them due to their disability. They also stated that this attitude was changed when the persons with SCI engaged in any work.

So it can be inferred that due to family members, neighbors, and relatives' negative attitude hampers person's QOL. Such negative social situations produce considerable risk for surviving. But there is a possibility to change the negative attitude if the persons with SCI can engage in any activities. It is also indicated that maximum participants (9 out of 10) experienced negative attitude and less than half participant (4 out of 10) experienced positive attitude from their family member, neighbors, and relatives after SCI.

Category 6: Strategies to overcome these social problems

Coding	**P1**	**P2**	**P3**	**P4**	**P5**	**P6**	**P7**	**P8**	**P9**	**P10**
Awareness	√	√	√			√	√	√	√	√
Encouragement	√						√			
Education	√							√		√
Motivation	√									
Social support	√			√	√		√			√

Table-6: Types of strategies to overcome these social problems

From the table, it is shown that a large number of participants said that society people need to be aware of disability (SCI), their right, strength, capabilities and limitation. On the other hand half of participants claimed that they need social support to overcome these social problems. Most of the participants (08 out of 10) said that,

"Firstly community people, family members, and relatives should be aware of disability. Everyone should understand their condition; they should take him forward and encourage him. They should change their mentality and treat as a human. If they give inspiration and motivation then all problems can be solved."

In this study person with SCI reported limited opportunities and negative outlook as a primary barrier to fully participation in their home and community. But they also suggested that if their family members, neighbors, relatives and other community people could know and aware about disability then their social barriers would be removed and they could lead a normal life in society as before. According to The United spinal association (2015), to educate members, other healthcare professionals, patients and their families as well as the public about all aspects of spinal cord injury and its consequences in order to prevent injury, improve care, increase availability of services and maximize the injured individual’s potential for full participation in all areas of community life. In a study Levins, Redenbach & Dyck (2004) resulted that friends, family, and rehabilitation professionals might be able to develop more appropriate ways to enable persons with SCI and they might be able to create opportunities for the persons with SCI’s physical activity that will improve their participation as well as create a full inclusion and meaningful life in the society. In another study Fatih et al. (2007) explained that the lack of family role seems to result in a lower life expectancy.

Half of the participants (5 out of 10) said that,

“If everyone support me and always help me, I can live with together. When I want to attend any programs that time everyone can help me. E.g. if I want to take any job, Government, my chairman, Disability policy, rights, MP can help me. In this way, I think I can lead my normal life.”

The positive attitude of the society towards the persons with SCI is very much important for their participation in the society. Awareness, social support, motivation, welcoming approach and accessibility environment are very important for the activity participation in the society after SCI. Good policy from the government, positive attitude of society peoples and family members can help to overcome the problems. Accessible environment (like- social support, encouragement, education, motivation, and awareness) can help the persons with SCI in their community to overcome challenges (Targett, Wehman, Mckinely, & Young, 2005, p.151). So it is determined that family members play an important role to minimize the social problem in the life of SCI population. Thus, the family member, neighbors, and community people should be aware of disability. Then they can get financial or mental support from family members and it will be helpful to overcome those barriers, lead a good QOL and participate in society.

So it can be determined from the study that to overcomes these social problems, society people need to be aware and educated about the SCI, their right, strength, capabilities and limitation at first and besides this they also need social support.

CHAPTER 5

LIMITATIONS AND RECOMMENDATIONS

5.1. Limitations

There are some limitations which were unconditionally taken by the study into account during the study period and here always tried to consider the limitations during the period of study. These are given below:

- In this research study, only men with Paraplegic SCI were included. So it is not possible to generalize both groups of people (male and female).
- The investigator didn’t direct observed the participant’s daily participation in society.
- Participants were collected only from three areas (Savar, Dhamrai, Manikganj Thana). So, it is difficult to represent the whole Bangladesh.

5.2. Recommendations

5.2.1. Recommendations for Occupational therapists (OTs) in Bangladesh

OTs should implement a broader role and holistic treatment techniques for the persons with SCI. They need to update their knowledge in this area and should raise awareness among the family, relative and neighbor to reduce, mental stress, and social strain. They also need to concentrate more on this issue during the working period. If they do not involve with the persons with SCI and the people surrounding them, it would not be significant. For this reason, it is necessary to involve them in accessibility, changing mentality, peer support, positive thinking, coping strategies, etc.

5.2.2. Recommendations for further research

- To use quantitative cross-sectional study.
- Social experiences of women with paraplegic SCI.

CHAPTER 6
CONCLUSION

Persons with SCI seem to face various critical obstacles such as poor social culture to deal with them, poor urban planning for the SCI, and different types of problems in the society. SCI has impact on both an individuals and his family socially, psychologically, and economically that causing mental distress for them and failure to lead in their primary struggles to achieve participation in activities and lead a successful independent life. A wide range of alternative strategies and techniques can be used by people with SCI to overcome activity limitations, including learning new techniques for participating activities. Participation in social activities should be recognized as an adjunct to current SCI rehabilitation programs, with the potential to contribute to improving their participation. It provides support and advice for persons with SCI to learn new and alternative ways of carrying out activities. So proper rehabilitation service (including awareness, education, and encouragement), family member, and community people supports can facilitate them to cope and overcome these obstacles as much as possible. It also makes sure the successful community participation that ensures individuals are able to generalize their learning across a range of different environments.

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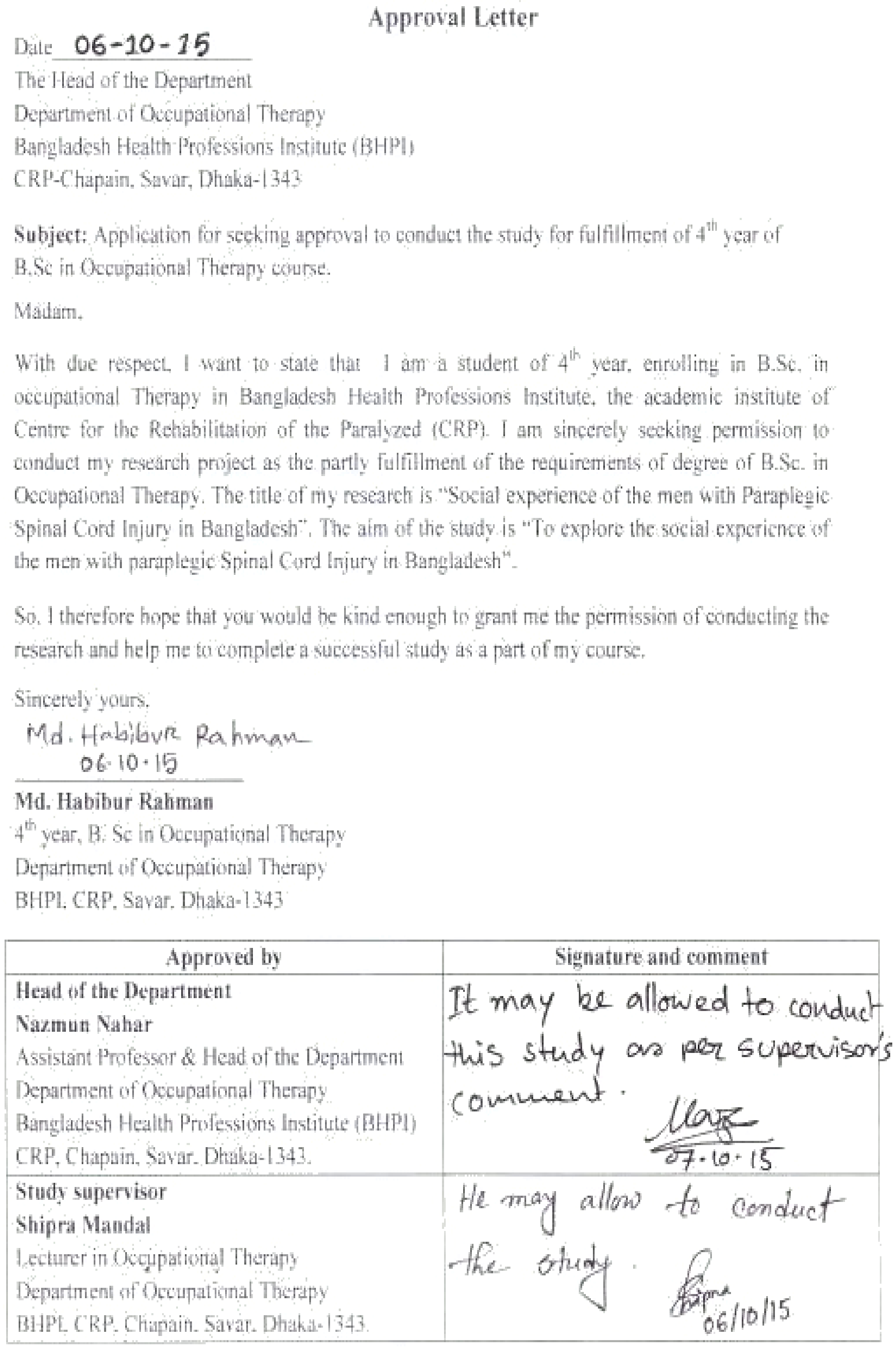
APPENDIX-1

Approval letter for conducting research



Approval Letter

Date 06-10-15

The Head of the Department
Department of Occupational Therapy
Bangladesh Health Professions Institute (BHPI)
CRP-Chapain, Savar, Dhaka-1343

Subject: Application for seeking approval to conduct the study for fulfillment of 4th year of B.Sc in Occupational Therapy course.

Madam,

With due respect, I want to state that I am a student of 4th year, enrolling in B.Sc. in occupational Therapy in Bangladesh Health Professions Institute, the academic institute of Centre for the Rehabilitation of the Paralyzed (CRP). I am sincerely seeking permission to conduct my research project as the partly fulfillment of the requirements of degree of B.Sc. in Occupational Therapy. The title of my research is "Social experience of the men with Paraplegic Spinal Cord Injury in Bangladesh". The aim of the study is "To explore the social experience of the men with paraplegic Spinal Cord Injury in Bangladesh".

So, I therefore hope that you would be kind enough to grant me the permission of conducting the research and help me to complete a successful study as a part of my course.

Sincerely yours,

Md. Habibur Rahman
06.10.15

Md. Habibur Rahman
4th year, B. Sc in Occupational Therapy
Department of Occupational Therapy
BHPI, CRP, Savar, Dhaka-1343

Approved by	Signature and comment
Head of the Department **Nazmun Nahar** Assistant Professor & Head of the Department Department of Occupational Therapy Bangladesh Health Professions Institute (BHPI) CRP, Chapain, Savar, Dhaka-1343.	It may be allowed to conduct this study as per supervisor's comment. 07.10.15
Study supervisor **Shipra Mandal** Lecturer in Occupational Therapy Department of Occupational Therapy BHPI, CRP, Chapain, Savar, Dhaka-1343.	He may allow to conduct the study. Shipra 06/10/15

APPENDIX-2

Permission letter for data collection from BHPI

বাংলাদেশ হেল্‌থ প্রফেশন্স ইনষ্টিটিউট (বিএইচপিআই)
BANGLADESH HEALTH PROFESSIONS INSTITUTE (BHPI)
(The Academic Institute of CRP)
CRP-Chapain, Savar, Dhaka, Tel: 7745464-5, 7741404 , Fax: 7745069
BHPI-Mirpur Campus, Plot-A/5, Block-A, Section-14, Mirpur, Dhaka-1206. Tel: 8020178,8053662-3, Fax: 8053661

তারিখ ঃ ১৪.১০.২০১৫

প্রতি

সহকারী ম্যানেজার,

রিহেবলিটেশন উইং,

পক্ষাঘাতগ্রস্তদের পুনর্বাসিন কেন্দ্র,

সিআরপি,চাপাইন, সাভার ,ঢাকা - ১৩৪৩।

বিষয় ঃ রিসার্চ প্রজেক্ট (dissertation) এর জন্য আপনার প্রতিষ্ঠান সফর প্রসঙ্গে।

জনাব,

আপনার সদয় অবগতির জন্য জানাচ্ছি যে, পক্ষাঘাতগ্রস্তদের পুনর্বাসন কেন্দ্রে-সিআরপি'র শিক্ষা প্রতিষ্ঠান বাংলাদেশ হেলথ্ প্রফেশনস্ ইনষ্টিটিউট (বিএইচপিআই) ঢাকা বিশ্ববিদ্যালয় অনুমোদিত বিএসসি ইন অকুপেশনাল থেরাপি কোর্স পরিচালনা করে আসছে।
উক্ত কোর্সের ছাত্রছাত্রীদের কোর্স কারিকুলামের অংশ হিসাবে বিভিন্ন বিষয়ের উপর রিসার্চ ও কোর্সওয়ার্ক করা বাধ্যতামুলক।

বিএইচপিআই'র ৪র্থ বর্ষ বিএসসি ইন অকুপেশনাল থেরাপি কোর্সের ছাত্র মো: হাবিবুর রহমান তার রিসার্চ সংক্রান্ত কাজের জন্য আগামী ১৫.১০.২০১৫ তারিখ থেকে ৩০.১১.২০১৫ তারিখ পর্যন্ত সময়ে আপনার প্রতিষ্ঠানে সফর করতে আগ্রহী।

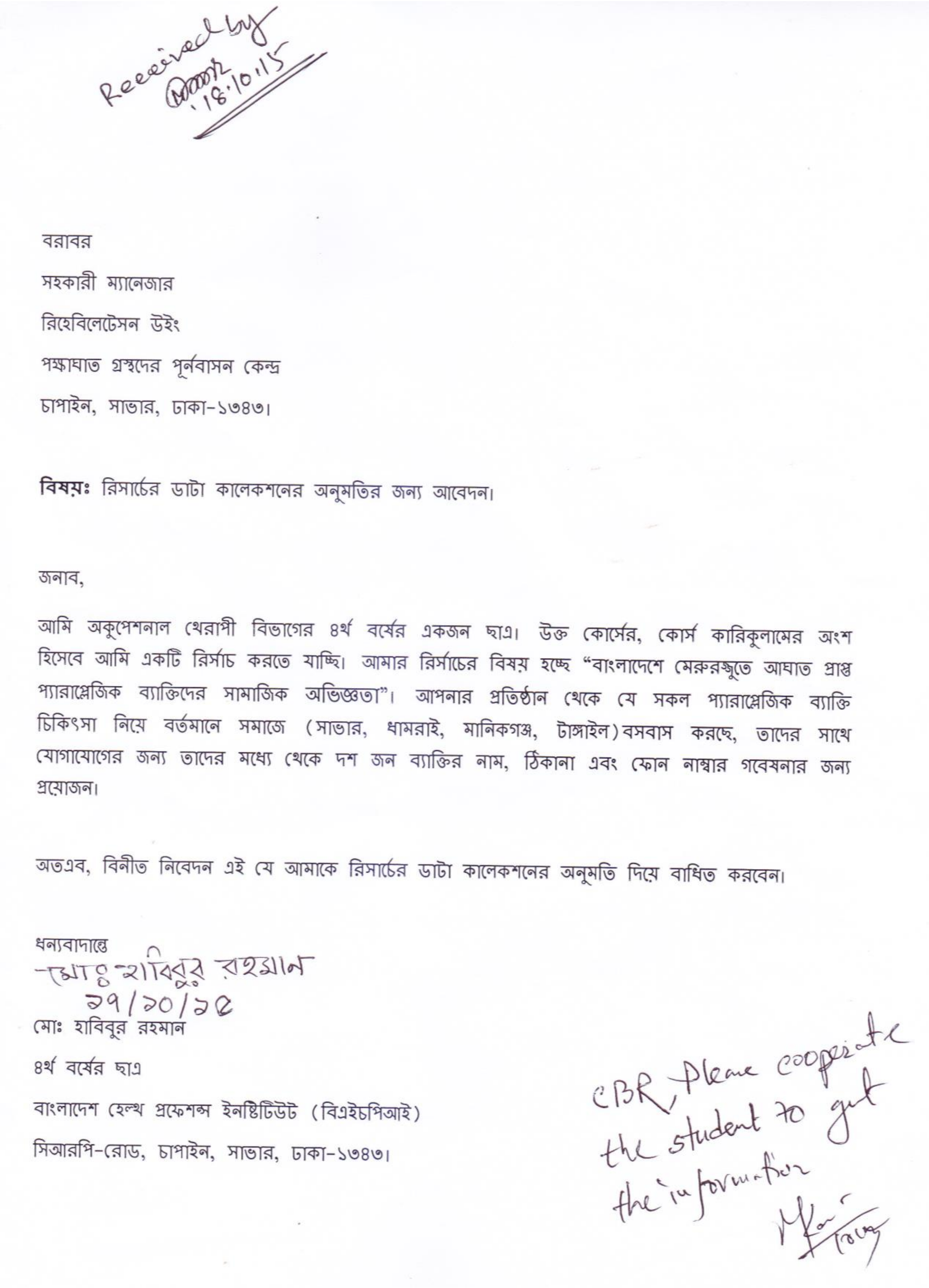
তাই তাকে আপনার প্রতিষ্ঠান সফরে সার্বিক সহযোগীতা প্রদানের জন্য অনুরোধ করছি।

ধন্যবাদান্তে

অধ্যাপক ডাঃ এম এ কাদের
অধ্যক্ষ
বিএইচপিআই।

APPENDIX-3

Permission letter for data collection from Rehabilitation Wing of CRP



Received by
18.10.15

বরাবর

সহকারী ম্যানেজার

রিহেবিলেটেসন উইং

পক্ষাঘাত গ্রস্থদের পূর্নবাসন কেন্দ্র

চাপাইন, সাভার, ঢাকা-১৩৪৩।

বিষয়ঃ রিসার্চের ডাটা কালেকশনের অনুমতির জন্য আবেদন।

জনাব,

আমি অকুপেশনাল থেরাপী বিভাগের ৪র্থ বর্ষের একজন ছাত্র। উক্ত কোর্সের, কোর্স কারিকুলামের অংশ হিসেবে আমি একটি রির্সাচ করতে যাচ্ছি। আমার রির্সাচের বিষয় হচ্ছে “বাংলাদেশে মেরুরজ্জুতে আঘাত প্রাপ্ত প্যারাপ্লেজিক ব্যাক্তিদের সামাজিক অভিজ্ঞতা”। আপনার প্রতিষ্ঠান থেকে যে সকল প্যারাপ্লেজিক ব্যাক্তি চিকিৎসা নিয়ে বর্তমানে সমাজে (সাভার, ধামরাই, মানিকগঞ্জ, টাঙ্গাইল) বসবাস করছে, তাদের সাথে যোগাযোগের জন্য তাদের মধ্যে থেকে দশ জন ব্যাক্তির নাম, ঠিকানা এবং ফোন নাম্বার গবেষনার জন্য প্রয়োজন।

অতএব, বিনীত নিবেদন এই যে আমাকে রিসার্চের ডাটা কালেকশনের অনুমতি দিয়ে বাধিত করবেন।

ধন্যবাদান্তে

মোঃ হাবিবুর রহমান
১৭/১০/১৫

মোঃ হাবিবুর রহমান

৪র্থ বর্ষের ছাত্র

বাংলাদেশ হেল্থ প্রফেশন্স ইনষ্টিটিউট (বিএইচপিআই)

সিআরপি-রোড, চাপাইন, সাভার, ঢাকা-১৩৪৩।

CBR, Please cooperate the student to get the information

APPENDIX-4

Information Sheet

I am Md. Habibur Rahman, 4th year, Department of Occupational Therapy, Bangladesh Health Professions Institute (BHPI), the academic institute of Centre for the Rehabilitation of the Paralyzed (CRP). As a part of my academic issues, I have to conduct a research project in this academic year. So I will like to invite you to participate in my study titled **"Social experience of the men with Paraplegic Spinal Cord Injury in Bangladesh".**

Your participation in the study is voluntary. You can withdraw your participation in anytime. There is not the facility to get any pay by this participation. The study will never be any harm to you but it will help the service user to know your experience about the discharge process, which is very important for the service provider to plan for their future activities. It will also be helpful for the forthcoming service users.

Confidentiality of all records will be highly maintained. The gathered information from you will not be disclosed anywhere except this study and the study will certainly never reveal the name of participants.

If you have any query regarding the study, please feel free to ask to the contact information stated below:

Md. Habibur Rahman
4th year, B. Sc in Occupational Therapy
Department of Occupational Therapy
Bangladesh Health Professions Institute (BHPI),
CRP-Chaplain, Savar, Dhaka-1343

APPENDIX-5

তথ্যপত্র

আমি মোঃ হাবিবুর রহমান। বাংলাদেশ হেলথ প্রফেশন্‌স ইনস্টিটিউটের (সি.আর.পি এর শিক্ষা প্রতিষ্ঠান) অকুপেশনাল থেরাপী বিভাগে ৪র্থ বর্ষে অধ্যয়নরত। আমার প্রাতিষ্ঠানিক কার্যের অংশ হিসেবে চলতি শিক্ষাবর্ষে একটি গবেষনা করতে যাচ্ছি। যার শিরোনাম “বাংলাদেশে মেরুদন্ডে আঘাত প্রাপ্ত প্যারাপ্লেজিক ব্যাক্তির সামাজিক অভিজ্ঞতা”

গবেষনায় আপনার অংশ গ্রহন সম্পুর্ণ সেচ্ছায়। আপনি যে কোন সময় গবেষনায় আপনার অংশ গ্রহন করা থেকে বিরত থাকতে পারবেন। এই গবেষনায় অংশ গ্রহনে গবেষক আপনাকে কোন ভাবে আর্থিক সাহায্য প্রদানে করা হবে না। এই গবেষনায় অংশ গ্রহন কখনোই আপনার জন্য ক্ষতির কারন হবে না, কিন্তু এই গবেষনার মাধ্যমে সেবা প্রদানকারী সদস্যগন, আপনার অভিজ্ঞতার কথা জানতে পারবেন এবং প্রাপ্ত তথ্য সমূহ সেবার মানোন্নয়নে সাহায্য করবে। যা পরবর্তীতে অন্যান্য মেরুদন্ডে আঘাত প্রাপ্ত ব্যাক্তিদের ক্ষেত্রে ও সহায়ক হবে।আপনার কাছ থেকে প্রাপ্ত তথ্য সমূহ সর্বোচ্চ গোপনীয়তা রক্ষা করা হবে। অনুসন্ধানকারী এবং অনুসন্ধানকারীর সমন্বয়কারী ব্যতীত এই তথ্য গুলো কোথাও প্রকাশিত করা হবে না এবং গবেষণার কোথাও অংশ গ্রহনকারীর নাম প্রকাশ করা হবে না।

গবেষণা সম্পর্কিত যে কোন ধরনের প্রশ্নের জন্য নিম্নলিখিত ব্যাক্তির সাথে যোগাযোগ করার জন্য অনুরোধ করা যাচ্ছে।

মোঃ হাবিবুর রহমান
৪র্থ বর্ষ, বি.এস.সি ইন অকুপেশনাল থেরাপি
অকুপেশনাল থেরাপি বিভাগ
বাংলাদেশ হেলথ প্রফেশন্স ইনস্টিটিউট
পক্ষাঘাত গ্রস্থদের পুনর্বাসন কেন্দ্র (সি.আর.পি.)
চাপাইন, সাভার, ঢাকা-১৩৪৩।

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[*] Translated Copy

APPENDIX-6

Consent Form

This research project is part of Occupational Therapy course and the name of the investigator is Md. Habibur Rahman. He is a student of Bangladesh Health Professions Institute (BHPI) in B.Sc. in Occupational Therapy in 4th year. The study was entitled as **“Social experience of the men with paraplegic Spinal Cord Injury in Bangladesh.**” The aim of the study is to explore the **Social experience of the men with paraplegic Spinal Cord Injury in Bangladesh.**

In this study, I am ………………………………………………………. a participant and I have been clearly informed about the purpose and aim of the study. I will have the right to refuse in taking part any time at any stage of the study. I will not be bound to answer to anybody. This study has no connection with me and there will be no impact on me and my patient regarding treatment at present and in future.

I am also informed that all the information collected from the interview that is used in the study would be kept safety and maintained confidentiality. My name and address will not be published anywhere. Only the investigator and supervisor will be eligible to access the information for his publication of the research result. Your name and address will not be published anywhere of this study. I have been informed about the above-mentioned information and I am willing to participate in the study with giving consent.

Signature/Fingerprint of the Participant:	Date:
Signature of the Investigator:	Date:
Signature/Fingerprint of the witness:	Date:

APPENDIX-7

সম্মতিপত্র

এই গবেষনাটি অকুপেশনাল থেরাপীর একটি অংশ এবং অনুসন্ধানকারীর নাম মোঃ হাবিবুর রহমান। সে বাংলাদেশ হেলথ প্রফেশন্স ইনস্টিটিউটের (সি.আর.পি এর শিক্ষা প্রতিষ্ঠান) অকুপেশনাল থেরাপী বিভাগে ৪র্থ বর্ষে অধ্যয়নরত। এই গবেষণার শিরোনাম “বাংলাদেশে মেরুদন্ডে আঘাত প্রাপ্ত প্যারাপ্লেজিক ব্যাক্তির সামাজিক অভিজ্ঞতা”।

এই গবেষনাতে আমি একজন অংশগ্রহনকারী এবং পরিষ্কারভাবে এই গবেষণার উদ্দেশ্য সম্পর্কে অবগত। আমার যে কোন সময় এই গবেষণা থেকে নিজেকে সরিয়ে আনার অধিকার আছে। এ জন্য আমি প্রশ্নের উত্তর প্রদানের জন্য কারো কাছে দায়বদ্ধ না। এই গবেষণাটির সাথে আমার কোন সম্পৃক্ততা নেই। আমি আরো অবগত আছি যে, এই কথোপকথন থেকে নেওয়া সমস্ত তথ্যাবলী নিরাপদে এবং গোপন রাখা হবে। আমার নাম ও ঠিকানা কোথাও প্রকাশ করা হবে না। শুধুমাত্র অনুসন্ধানকারী এবং অনুসন্ধানকারীর সমন্বয়কারী সাথে এই গবেষণার পদ্ধতি সম্পর্কে অথবা যে কোন প্রশ্নের উওর জানার জন্য কথা বলতে পারব।

আমি উপরোক্ত তথ্যগুলো ভালোভাবে জেনে নিজ ইচ্ছায় এই গবেষণায় অংশ গ্রহন করছি।

অংশগ্রহনকারীর স্বাক্ষর/টিপসই	তারিখঃ
অনুসন্ধানকারীর স্বাক্ষর	তারিখঃ
সাক্ষ্য প্রদানকারীর স্বাক্ষর/ টিপসই	তারিখঃ

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[*] Translated copy

APPENDIX-8

Questionnaire

1. Do you face any difficulties in the community after spinal cord injury? Please explain your experience.
2. Is there any impact on social participation due to above-mentioned difficulty? Please explain.
3. What kinds of social activities or programs did you participate before spinal cord injury? Please explain.
4. Do you participate in any social activities or programs after spinal cord injury? Please describe.
5. Do you face any social problems during participating in social activities or programs? Please explain.
6. Are there any changes in attitude of your family members after spinal cord injury? Please explain.
7. What kind of attitude do your neighbors show after spinal cord injury? Please explain.
8. Is there any impact on your relationship with your relatives after spinal cord injury? Please explain.
9. Please explain how you try to deal with your social problem.
10. Please explain possible way to overcome these social problems?

APPENDIX-9

গবেষণার প্রশ্নাবলী

অংশগ্রহণকারীর নামঃ .... ঠিকানাঃ.....................

১. মেরুজ্জুতে আঘাত পাওয়ার পর বর্তমানে আপনি কি কোন ধরনের সমস্যার সম্মুক্ষীন হচ্ছেন? অনুগ্রহ করে আপনার মতামত ব্যাখা করুন।

২. উপরোক্ত সমস্যা গুলোর কারনে আপনার দৈনন্দিন কাজকর্মে কি কোন ধরনের প্রভাব পড়ছে? বিস্তারিত ব্যাখা করুন।

৩. মেরুজ্জুতে আঘাত পাওয়ার পূর্বে আপনি কি কোন সামাজিক কর্মকান্ড/অনুষ্ঠানে অংশ গ্রহন করতেন? অনুগ্রহ করে বিস্তারিত বলুন।

৪. মেরুজ্জুতে আঘাত পাওয়ার পর বর্তমানে আপনি কি কোন সামাজিক কর্মকান্ড/অনুষ্ঠানে অংশ গ্রহন করছেন? অনুগ্রহ করে বিস্তারিত ব্যাখা করুন।

৫. সামাজিক কর্মকান্ড/অনুষ্ঠানে অংশগ্রহন করতে কোন ধরনের সমস্যার সম্মুক্ষীন হলে অনুগ্রহ করে আপনার মত প্রকাশ করুন।

৬. মেরুজ্জুতে আঘাত পাওয়ার পর আপনার প্রতি পরিবারের সদস্যদের আচার-আচরনে কি ধরনের পরিবর্তন এসেছে? অনুগ্রহ করে ব্যাখা করুন।

৭. আপনার প্রতি প্রতিবেশিরা কি ধরনের মনোভাব প্রকাশ করছে তা অনুগ্রহ করে ব্যাখা করুন?

৮. আপনার আত্নীয়-সজ্নের সাথে সম্পর্কের কোন প্রভাব পড়েছে কি? অনুগ্রহ করে আপনার মতামত ব্যাখা করুন।

৯. মেরুজ্জুতে আঘাত পাওয়ার পর বর্তমান সমস্যা গুলোর সাথে আপনি কিভাবে নিজেকে মানিয়ে নিচ্ছেন তা অনুগ্রহ করে বিস্তারিত ব্যাখা করুন।

১০. এই সমস্যা গুলো উত্তরনের উপায় সম্পর্কে বিস্তারিত আলোচনা করুন।

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[*] Translated Copy