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**University of Dhaka**

**PERCEPTION ABOUT ACCESSIBILITY IN THE COMMUNITY AMONG  
WHEEL CHAIR USERS WITH SPINAL CORD INJURY**

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**Perception about accessibility in the community among wheel chair users with spinal cord injury.**

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## Declaration

I declare that this work presented here is done by me. I also declare that all sources used have been cited appropriately. The information and data given in this report is authentic to the best of my knowledge. Any mistake and inaccuracies are my own. I also declare that for my publication, presentation or dissemination of information of the study. I would be bound to take written consent from the Department of Physiotherapy, Bangladesh Health Profession Institute (BHPI).

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## Acronyms

- BHPI:** Bangladesh Health Professions Institute
- BMRC:** Bangladesh Medical Research Council
- CRP:** Centre for the Rehabilitation of the Paralysed
- ICF:** International Classification of Functioning
- IRB:** Institutional Review Board
- QCA:** Qualitative Content Analysis
- SCI:** Spinal Cord Injury
- UK:** United Kingdom
- USA:** United States of America
- WHO:** World Health Organization



## Abstract

*Purpose:* To find out the perception about accessibility in the community among wheel chair users with spinal cord injury. *Objectives:* To identify the structural barriers in house, to identify the perception about accessibility in community, to detect the environmental barrier in community, to identify the barrier in spiritual and cultural participation, to find out the perception about family and social support. *Methodology:* A qualitative descriptive approach with semi structured interview used to conduct the study where eleven participants with SCI who had completed their rehabilitation from Centre for the Rehabilitation of the Paralyzed (CRP) were participated selected by purposive sampling method. The data were collected by using a semi structure open ended questionnaire form and thematic analysis to determine key theme arising from individuals with SCI. *Result:* Participants mentioned a number of barriers they face because of inaccessible accommodation in their house environment such as kitchen, limited access in toilet, inadequate space in room, narrow doorway. They also remarked that environmental barrier, inadequate ramps and faulty outdoor construction, hostile weather also a major barrier in their community participation. It identifies that, comparatively women wheel chair user experienced more barrier than man. Stigmatized social attitude and ignorance seems also a major barrier in community participation. They also remarked that, supportive family and good social relationship act as a strong facilitator for wheel chair user SCI person for their community participation. *Conclusion:* This study highlighted that wheel chair user's perception about their inadaptable accommodation, inaccessible environment in community participation, stigmatized social attitude and also strong contribution of personal care giver in community participation. Participators felt that if society as well as government can legislation to advocate persons with disabilities for equal rights with the aim of moving towards an equal accessible society, these barriers can be removed.

Key word: Perception, wheelchair user, accessibility, spinal cord injury.

## **1.1 Background**

The incident of a spinal cord injury prompts to a tremendous change to individual's lifestyle. It is an unpredictable and in some cases life alternating even for persons and their family members. The spinal cord is the downward continuation of medulla that beginning from foramen magnum to the cauda equina. (Nas et al., 2015). The major function of spinal cord is to conduit through nerve signals in which motor and sensory information travels between brain and body. Longitudinally oriented spinal tracts (white matter) surrounding central areas (gray matter) contained by the spinal cord where most spinal neural cell bodies are placed. (Krishblum et al., 2011).

The spinal cord injury involves erosion to any part of spinal cord temporarily or permanently. This incident blocks the sensory and motor signals carrying at the lesion site. The amount of people around the world living with disability is more than a billion. Spinal cord injury certainly a part of them. It persisted psychological, functional, social, economical and permanent neurological effects universally over time.

However, spinal cord injury can proceed from both traumatic and non-traumatic. It is predicted that humans over worldwide are living with long-term disability following spinal cord injury is more than twenty seven million. In this population almost 90% end from the result of trauma and 10% end from the result of secondary complication (Bradbury and Burnside, 2019). Traumatic spinal cord injury is life threatening event, combination of compression, laceration, distraction or shearing, resulting from disruption of the spinal cord tissue. It occurs most commonly motor vehicle accidents, falls, acts of violence, sports and recreation injuries. In the other hand, tumors and degenerative diseases in the spinal column caused by vascular and autoimmune diseases that arise in non-traumatic spinal cord injury (New et. at 2015).

Even people with spinal cord injury can survive from long term complication, disability, morbidity and mortality. These complications create huge additional expenses, new problems and challenges to spinal cord injury survivors and their health care providers. Spinal cord injury are susceptible to develop atelectasis, pneumonia, urinary tract infection, autonomic dysreflexia, deep vein thrombosis, pulmonary embolism, postural hypotension, neuropathic pain, obesity, depressive disorder and spasticity. These complications have been corresponding with poorer survival, environment and long time hospital stay. The development of rehabilitation programs and regular follow up can increase life expectancy of people with spinal cord injury. (Kemal et al., 2015).

In such circumstances, the interdisciplinary method of the rehabilitation team along with the affected person and circle of relatives is essential for the premiere care of a person. Every group member performs a vital role on this technique presenting care and family training. Although, Rehabilitation process and treatment period following SCI is long lasting, expensive, and exhausting in both complete and incomplete injury. Though it is an extended procedure so, patient and care givers both need to keep patience and motivation (Steven et al; 2007).

However, Rehabilitation process actively encourage people with spinal cord injury to being a part of a family, community life, fulfilling social roles, accomplishment of daily activities, responsibilities, being an active and contributing member in community. But the people who are struggling with spinal cord injury and also living in community their quality of life is below than others. One of the prime object of rehabilitation program following SCI intends to accomplish not only physical, psychological and social consequences but also potential influences reintegration into the community.

As the individual is a social being, they also participating in the construction and maintenance of concepts, status and social values. These perception can be rife with stereotypes and prejudices on both sides. Basically, the person who affected by spinal cord injury hardly need a wheelchair for his locomotion, mobility tasks, independence in community participation. It expresses the functional disability and disadvantages that people facing physical, sensory and psychological aspects, reinforcing segregation and

discriminatory feeling from society (Costa et al., 2010). In community participation, a wheel chair user person need to improve other services for better locomotion also enhance social functioning and quality of life (Williams et al., 2017). It is estimated that, the world health organization (WHO) released rules on the provision of low income manual wheelchairs and training package for service suppliers (Mattick., 2017).

People with SCI have indicated worldwide that rehabilitation does not prepare them properly for community living. Only (5-15) % of individuals with disabilities low and middle income countries have adequate access to supportive device in terms of facilities (Stucki and Bickenbachi et al., 2017). Using wheelchair for movement on their societies, spinal cord injury persons frequently encounter challenges. It includes not only inaccessible accommodation, environmental barriers, faulty construction, poorly maintained sidewalks but also social stigma and family support. That can reduce their mobility. Stigmatize social attitude and cultural barrier compromise the independence as well as capacity of a person to engage in physical and community participation (Harris et al., 2015).

After all, in developing countries primary and environmental barriers have profoundly impact on community participation in wheel chair user SCI persons. Awareness is needed to promote health seeking attitudes to empower individuals in the community with SCI, enhance health care provider, removes barriers, adequate social service, positive attitude can facilitate SCI population more involvement in community participation.

## **1.2 Rationale**

Spinal cord injury (SCI) creates deep modification in almost all the body structure and functional capability of individuals suddenly onset and of an unexpected nature. It is a divesting condition that has an impact on not only physiological aspects but also psychosocial condition in community participation. The opportunity to engage meaningful life as well as contribution of social participation may alter or decrease after SCI. Without support their family and social communication of individuals are undergo the adjustment process to fulfill their requirement following injury. Moving around home and community with daily basis is a core activity for wheelchair user spinal cord injury persons. For good community participation and to improve functional capability, to become more independent, to increase their potentiality wheelchair is an important therapeutic equipment for individuals with SCI. Accessibility in physical and structural environment is a major barrier in community participation. People with SCI, both male and female faces many challenges because of inaccessible environment, lack of community resources, and inadaptable accommodation in both urban and rural area, different culture and social beliefs. This factors can hinder there community participation. The international classification of functioning disability and health estimated that, there is a dynamic factors interaction in between person's health condition, environmental factors and personal factor.

The World Health Organization (WHO, 2011) estimated that 15% of the world's population, or one billion people, have a disability such as spinal cord injury; mobility disability, auditory, visual, communication, cognitive or learning impairment. According to the United Nations Development Program (2007), 80% of people with disabilities (800 million) live in developing countries or resource-limited environments in which the infrastructure is underdeveloped or inadequate to support the provision. Disability is strongly associated with poverty, and most people in less-resourced settings who need wheelchairs are unable to buy their own wheelchairs. Approximately 15% of the world's population have some type of disability, and 1% of the population globally need wheelchairs for increased mobility. The United Nations has affirmed the right for persons with disabilities to have access to affordable mobility devices, social inclusion, and

community participation. A non-ambulatory person who uses a wheelchair and lives in a community with adequate sidewalks and transportation may experience limitations in mobility differently compared to a person with a similar injury living in a community that lacks these features. Community support encourages participation of SCI person as it helps people develop strong coping skills, creates a feeling of autonomy, motivates patients to stay healthy and relieve stress by facilitating healthy behaviors. Through increasing this knowledge, rehabilitation professionals, policy makers, and other stakeholders can be better informed in order to address such issues and help facilitate the transition of survivors of SCI back to the community.

As Bangladesh is a developing country and trying to develop health care system. If we want to give appropriate rehabilitation of spinal cord injury patients then we have to know the barriers and facilities in accessibility of community participation. CRP managed the patients with multi and interdisciplinary approach which emphasis on the development of community based rehabilitation programs but there has been no specific research of is conducted to identify the barriers in accessibility in community participation based on perspective of spinal cord injury patients in Bangladesh. Through the study of patient's perception about their accessibility of community participation. If the barriers and facilities are identify and generate the importance to focusing on this expect an overcoming strategy can be undertaken by the professionals so that the sufferers can participate themselves successfully and can lead a better productive life as well as the working area of the physiotherapist will broaden in this spectrum.

### **1.3 Research question**

What are the perception about accessibility in the community among wheelchair users with Spinal cord injury?

## **1.4 Study objectives**

### **1.4.1 General objective**

- I. To explore the perception about accessibility in the community among wheel chair user person with SCI.

### **1.4.2 Specific objectives**

- I. To find out the socio demographic information about patient's.
- II. To identify the structural barriers in house.
- III. To detect the environmental barrier in community.
- IV. To identify the barrier in spiritual and cultural participation.
- V. To find out the perception about family and social support.



## **1.6 Operational Definition**

### **Perception:**

Perception is the capacity to see, listen, or ended up mindful of something through the senses or the way in which something is respected, understood or interpreted.

### **Spinal Cord Injury (SCI):**

When the spinal cord is injured by any reasons like trauma or disease that result sensory and motor loss is called spinal cord injury.

### **Tetraplegia:**

This term refers to impairment or loss of motor and /or sensory function in the cervical segments of the spinal cord due to damage or neural elements within the spinal canal. Injury to the spinal cord in the cervical region is associated with loss of muscle strength in all four extremities.

### **Paraplegia:**

This term refers to impairment or loss of motor and /or sensory function in the thoracic, lumber or sacral segments of the spinal cord, secondary to damage of neural elements within the spinal column.

### **Accessibility**

Accessibility refers to the design of products and environments for people with disabilities. Examples include wheelchairs, entryway ramps, hearing aids, and braille signs.

### **Community**

A community is a small or large social unit (a group of people) who have something in common, such as norms, religion, values, or identity and the communities share a sense of place that is situated in a given geographical area (e.g. a country, village, town, or neighborhood).

Spinal cord injury (SCI) is a kind of high disabling injury; it not only can lead to damage or loss of sensation and motor function, but also may lead to multiple organ dysfunction (Huang and Mao et al., 2015). Spinal cord injury is destructive and unpurchaseable situation which occur unexpectedly in human and social life. Physical disabilities can either be acquired or are congenital, and the impact they have upon function and independence can vary considerably from individual-to-individual (Stephens, et al., 2012).

Traumatic spinal injury commonly leads to significant impairment in the quality of life. More than 10% of trauma patients sustain spinal injury and they have a higher mortality rate compared to other trauma (Bouyer, et al., 2019). The incidence of spinal fractures is reported to vary between 16 and 64/100,000 depending on the study area and population concerned (Hasler et al.,2019). Internationally, most of the injuries are caused by road traffic accidents (RTAs), together with low and high falls. Road traffic and high fall accidents are typical etiology in young patients, whereas the role of low falls and associated osteoporosis increases trauma in older population. Spinal fractures are often associated with other injuries as 30% to 55% of patients are reported to have at least one associated injury (Wang et al., 2019).

The most common affected age group in this study was 20–39 years followed by 50–59 years. It can be seen that 56.14% patients come under the 20–39 years age group, signifying higher incidence in young, active, and productive population of the society. Injury in 50–59 years age group was mostly due to fall. The male–female ratio ranged from 3.0:1 to 4.3:1 among developed countries. With regard to developing countries, China reported the lowest male-female ratio 1.73:1, whereas Pakistan and Bangladesh had the highest ratio 7.55:1 and 7.5:1, respectively (Obalum et al., 2009). According to WHO November 2013, every year around the world, between 2, 50,000 and 50, 00,000 people suffer a spinal cord injury. The majority of spinal cord injury of SCI are due to preventable causes such as, road traffic crashes, falls or violence. People with SCI are two to five times more likely to die prematurely than people without a spinal cord injury, with worse survival rates in low

and middle income countries. Males are most at risk in young adulthood (20-29 years) and older age (70+). Females are most at risk in adolescence (15-19) and older age (60+). Studies report male-to-female ratios of at least 2:1 among adults, sometimes much higher (WHO, 2013).

Most of the developed countries had higher percentages of tetraplegia. But most of the developing countries had the opposite condition where percentages of paraplegia were higher than those for tetraplegia (Wen-Ta Chiu, et al., 2010). In Europe with an incidence variation from 10.4 per million per year to 29.7 per million per year (Tricot, et al., 1981). Five studies were based on information from Northern America (Alaska, Mississippi, Kentucky, Indiana, Ontario, and Alberta), showing an incidence between 27.1 per million per year and 83 per million per year (Silberstein, et al., 1995). A report from the NSCISC estimated the annual incidence of SCI, not including those who die at the scene of the accident, to be approximately 40 cases per million population or approximately 11000 new cases each year.

In Asia (Jordan, Japan, Taiwan, and Fiji Islands) with an incidence between 18.0 per million per year and 40.2 per million per year (Maharaj, et al., 1996) From Australia, there was one study, estimating the age-standardized SCI incidence at 14.5 per million per year. The crude SCI incidence is 16.8 per million per year (Surkin, et al., 2000). Literature data show that two-thirds of SCI patients are paraplegic, and one-third is tetraplegic whereas in older studies, the proportion of paraplegics used to be up to 90%. A very high percentage of tetraplegics was found in the study from the Netherlands (57%). A demographic study by Jackson 38 reports a tetraplegia percentage of 54.1% in the United States. Before 30 years, 40% of SCI patients had a complete lesion. Recent studies show an increase in complete SCI to 50%. Except for Portugal and Taiwan, the mean age of patients sustaining their injury at is in their early thirties. This was also reported as such in older studies. The NSCISC fact sheet states that from 1973 to 1979, the average age at injury was 28.7 years and that it has risen to 37.6 years in 2000. The sex distribution (men/women) of SCI in recent studies is 3.8/1, where it used to be 4.8/1. Men seem to be still more at risk for SCI. However, women do seem to catch up slowly. We can conclude that most patients with SCI are young men, in the beginning of their thirties, more likely paraplegic, complete or

incomplete. In most of the developing countries, the majority of patients were young adults (age group 20–40 years). The mean age of incident cases of SCI patients seems to be higher in developed countries possibly due to longer life expectancies, a higher mean age of population and better medical care systems (Ackery, et al., 2004). The male-to-female ratio in developing countries (82.8% males; M/F: 4.8/1) is higher compared to developed ones as most studies in developed countries have a male-to-female ratio of approximately 3–4 (Elovic, et al 2004). This may reflect a higher level of social and sport activities of females in developed countries compared to developing ones. Additionally, women in developing countries often have more traditional home-based activities, which likely diminishes their risk of developing an SCI (Hoque, et al., 1995).

In Bangladesh the number of female spinal cord injury patients is on rise according to different published article. In our country traumatic spinal cord injury lesions, paraplegic 60% and tetraplegic 60%. Among the traumatic patients (72%), there were three main causes of injury. Seventy-six (43%) resulted from a fall from a height (such as a tree). Thirty-seven injuries (20%) were associated with falling while carrying a heavy load on the head which is a common practice in Bangladesh). Thirty-three (18%) were a result of a road traffic accident. Eleven patients (6%) formed a very diverse group which included assault, stab injury, sports injury and bull attack (Hogue, et al., 1995). Among the 68 patients (28%) in the non-traumatic spinal cord lesion group the main cause was Pott's disease (19 patients 28%), followed by 14 patients with a tumour (21%), seven cases of transverse myelitis (10%), six from a prolapsed intra-vertebral disc (9%), four with Guillain Barre syndrome (6%) and one associated with cervical spondylosis (1%) (Parareya, et al., 1996).

Many studies of SCI were carried out in developed nations, especially in America, Canada and Australia. To the best of our knowledge, several reviews of SCI in China have been reported. In 2002, the incidence in Beijing was 60.6 per million, while it was 23.7 per million in Tianjin. In developed countries, the annual incidence was 20.7–83 per million in America and 8.0–130.6 in Europe (Furlan, et al., 2013). This indicate the incidence of SCI in China was similar with developed countries. And other studies have reported developing regions had lower incidence compared to developed countries (Chiu, et al.,

2010). Such difference might due to the development level of society and economy. In Europe and American, people are more likely to participate in risky activities like housing riding, rugby and skiing and these are high risk factors of SCI. In China, ages with peak incidence is different from other countries. Ages with peak incidence was varied from 30 to 60 years, while it was 20–29 in Aragon, Spain (1972–2008) and 16–31 in Thessaloniki, Greece in 2006 ( Castellote, et al., 2010). Most studies showed that male were at higher risk of SCI than female (Obalum, et al., 2010). These results were in accordance with present study in China. The ratio up to 5.71:1 in Tianjin. SCI can cause sensory or motor deficit and bladder dysfunction, so patients have high risks of complications. Pulmonary infection, urinary tract infection and bedsore are common complication. Body systems and their SCI complications include: urinary tract with infection, renal stone, hydro nephrosis, urinary incontinence, vesicouretrul reflux; gastrointestinal tract with constipation, hemorrhoids, stool incontinence, cholecystitis, appendicitis, upper gastrointestinal bleeding, superior mesenteric artery syndrome, pancreatitis, skin with pressure sore; cardiovascular system with autonomic dysreflexia, thromboembolism, pulmonary tract with infection, ventilatory failure, sleep apnea, musculoskeletal system with osteoporosis, muscular weakness, paralysis, atrophy, spasticity, pain; endocrine system with hypercalcemia; sexual organs with erectile dysfunction, male infertility; psychiatry with depression.

Approximately 15% of the world's population have some type of disability, and 1% of the population globally need wheelchairs for increased mobility, although precise estimates for less-resourced settings are unavailable. More than 300,000 wheelchairs are donated annually to low and middle income countries by international donors and charitable organization (WHO, 2011). Many individuals with a spinal cord injury (SCI) rely on their wheelchairs to complete daily mobility tasks. Unfortunately, the natural environment creates many mobility challenges for wheelchair users. A study found that wheelchair users reported curbs, uneven terrain, and travel surface as barriers to their mobility (Meyers, et al., 2002). Approximately 40% of participants were unable to maintain a stationary wheelie for 30 s (Michelle, et al., 2002).

In last decade, approximately 85,000 Canadians are living with a spinal cord injury. Each year 4000 new injuries are reported. Participation has been identified as the foremost outcome of the rehabilitation process for health care professionals working with individuals with disabilities (Noreau, et al., 2005). It has been used synonymously with various other terms, including social adjustment, independent living, social functioning, engagement and community integration. The International Classification of Functioning, Disability and Health defines participation as ‘involvement in a life situation’ and distinguishes objective involvement as the object of interest. Participation is viewed as a continuous process rather than solely a rehabilitation outcome and consistent with the social model of disability, focuses on the lived experience of individuals participating in their lives and communities. Studies among individuals with SCI have predominately used society-perceived perspectives to explore participation (Harris, et al., 2007).

Although Spinal cord injury is a serious divesting condition, So Persons with a SCI often remain dependent on services like wheelchairs, adapted cars and domestic adaptations for the rest of their lives. 82.4% had one or more wheelchairs and 60.0% were completely wheelchair-dependent. According to Van Asbeck, Some research show that, In Netherlands problems with domestic adaptations, wheelchairs and equipment needed for resuming work, household or sports. Harvey found that 60.2% of all spinal cord injured, and 82.0% of complete tetraplegics, had one or more home modifications. However, a comparable number of respondents, 23.0% or 54.5% of complete tetraplegics, built additional rooms or new houses. In Japan, where nearly the same percentage of respondents (87%) altered their houses and somewhat more respondents (43%) extended their houses (Nakajima, et al., 2013). Nearly 80% of all respondents indicating that their houses were sufficiently adapted, but also with a substantial group of respondents (38%) who said that they were lacking one or more adaptations.

In US, about half of the persons with assistive technology and more than three-fourths of the persons with home accessibility features, purchased them themselves or with the help of their families without contribution from third-party payers (LaPlante, et al., 2012). In Americans, More than 2.5 million need assistive technology devices that they do not have, mostly because they cannot afford them (Forrest, et al., 2010). Numerous disability studies

found that among the social factors that hinder people with disabilities from participating in every day's mainstream are inaccessible built environment, ignorance in the policy making system, lack of employment opportunity and public ignorance, rights and their capabilities ( Kadir, et al., 2018).

In developing countries, Spinal cord injury can be neglected and patients may present late without any or with inadequate treatment (Chhabra and Arora, 2012). Studies show that in rural areas people with SCI have a higher risk of neglected care and a higher incidence of complications. The sudden onset of SCI is tragic and has a critical impact on the patient and significant others related to them. Existence of barriers in the environment gives rise to a sense of discrimination in people with SCI, prevents their social participation, limits their choices and foils their attempts to lead an independent life and the ability to care for themselves.

**3.1 Study design**

The researcher selected qualitative methodology for this study, because it is helpful to find out the perceptions of people in particular settings and to understand their perspective. Qualitative research focuses in understanding a research query as a humanistic or idealistic approach. Qualitative method is used to understand people's beliefs, experiences, attitudes, behavior, and interactions (Pathak, et al., 2013). The integration of qualitative research into intervention studies is a research strategy that is gaining increased attention across disciplines. They help reveal the behavior and perception of a target audience with reference to a particular topic. Qualitative researchers use their own eyes, ears and intelligence to collect data in depth perceptions and descriptions of target populations, places and events (Crossman, et al., 2019). In clinical trials, qualitative research can have a great impact on data collection, its analysis and the interpretation of results. Qualitative studies should be well-designed and the aims, procedures of the study should be meticulously adjudicated (Popy, et al., 2006).

**3.2 Study area**

The research took place in the community setting after completion of their full rehabilitation from Centre for the Rehabilitation of the Paralysed (CRP).

**3.3 Study population**

Spinal cord injury patients who have been completed their full rehabilitation from CRP and have been return to their communities.

**3.4 Participant selection procedure**

Participants were selected from the population by using purposive sampling technique. Purposive sampling based on some pre-defined inclusion criteria. The researcher selected the participant by purposive sampling because researcher had specific requirements and chose those who met the selection criteria. The inclusion criteria for participation in this study were the persons with SCI who have been completed their full rehabilitation at CRP,



Savar, Dhaka and at least 2 months resided in community. At first, investigator chose those patients who met the selection criteria from Community Based Rehabilitation (CBR) unit of CRP. Then collect the address of persons who met the selection criteria. After that, investigator took the permission to go to the participant's home in community by mobile phone contract with them. Participants who gave the permission to go to their home, investigator only select that participation.

#### **1.4.2 Inclusion criteria**

- I. Age between 20-65 years (can understanding the research question and can give the expecting answer).
- II. SCI persons who have already completed their rehabilitation from CRP and at least 2 months resided in community.

#### **3.4.2 Exclusion criteria**

- I. Patients who have mental disorders.
- II. SCI persons who complete their rehabilitation from other hospital or rehabilitation center.
- III. Patients age below than 20 and greater than 65 years.

#### **3.5 Sample size**

Eleven participants were taken as sample from community that was according to data saturation.

#### **3.6 Method of data collection**

Researcher conducted face to face interview with open ended question for data collection. With open ended question, participants get more freedom to explain their opinions. That face to face interview helps the researcher to observe the participants facial expression and non-verbal expression during interview period (Depoy & Gitlin, 2015). Before starting the formal interview, researcher ensured a quiet place by contacting with the regarding authority and built connection with the participants and made them comfortable for interview. The researcher explained the research question and aim of the study. Then the researcher used information sheet and consent form to take the permission of the participants. Next researcher asked questions. All question and information sheet was

developed into Bangla. Interview was conducted in Bangla and recorded by recorder of mobile phone. The interview conducted during daytime and the duration was approximately 20-30 minutes for each participant. Venue of interview was the community where the persons with spinal cord injury deal with their family but the place of interview depended on situation and permission of regarding authority.

### **3.7 Data collection tools and materials**

A phone recorder was used to record the interview of the participants. Pen, paper and clip board was used to write down observation notes. An information sheet and consent form was used for taking permission from the participants. An open ended question sheet was used to conduct the interview.

### **3.8 Questionnaire**

For data collection a semi-structured questionnaire was used. The questionnaire was formed based upon the related literature, determine of the study title and also pilot study.

### **3.9 Duration of data collection**

Data were collected from 20<sup>th</sup> April 2019 to 10<sup>th</sup> July 2019. Each participant provided particular time to collect data. Each questionnaire took approximately 20-30 minutes to complete.

### **3.9 Data analysis**

At first in data analysis, the researcher listened to the interviews several times from the tape recorder and then the interviewed data was transcribed in Bangla. The researcher checked the transcript to make sure that all the data was available in the transcript. Then three copies were made from the transcript and were given to eleven people for translation from Bangla to English. Then the data was analyzed by QCA. Data was analyzed by 3 stages: coding, categorizing and generating theme. After that, the investigator read all data repeatedly to find out the actual meaning of the participants expressions of what they wanted to say and organized them. Then major categories were found from the interview questions. The researcher was arranging all the information according to the categorization. Under these categories, the researcher coded all the information from the interviewed

transcript. After finishing the tabulation of coding, the researcher detected some important codes that made the themes of the study. At last, themes were identified and emerged as a process of interpretation.

### **3.11 Pilot study**

After getting approval for conducting the research and before starting the final data collection, researcher accomplished the pilot study with two participants. Pilot study was necessary as it helped the investigator to develop a final question and to collect data from participants easily. This study was performed to find out the difficulties that exist in the question. By this test, the researcher re-arranged and modified the question as required for the participants, so they can understand the question clearly.

### **3.12 Ethical consideration**

Ethical issues should consider strictly. So, before starting the study, a formal project proposal was submitted to the department of physiotherapy and after verifying the proposal, permission was taken from Institutional Review Board (IRB) of BHPI to continue the study. This study followed the World Health Organization (WHO) & Bangladesh Medical Research Council (BMRC) guideline and strictly maintained the confidentiality. After that, permission for data collection was obtained from the area where I conduct the study. The respondents were clearly informed about the aim and objectives of the study. After that they were interviewed following signing the consent form. The investigator has been ensured the confidentiality of participant's information, and shares the information only with the research supervisor.

The aims and objectives of the study should be informed to the subjects verbally. Before participating in the study the investigator had proved them a written consent form and explained them about it and then ask to sign as well as the researcher had also signed in the consent form. It was mentioned that the subjects had the rights to withdraw themselves from the research at any times. It was assumed to the participant that his or her name or address would not be used. Participation number were used in the notes and transcripts throughout the study. The information might be published in any normal presentation or seminar or written paper but they would not be identified and these would not cause any

herm to them. It was also ensured that every participant has the right to discuss about her problem with senior authority as related to this project.

### **3.14 Rigor of study**

The rigorous manner was maintained to demeanor the study. This study was conducted in a systemic way by next the steps of research under supervision of an experienced supervisor. During the interview session and analyzing data, never tried to influence the process by own value, perception and biases. Be accepted the answer of the questions whether they were of positive or negative impression. The participant's information was coded accurately and checked by the supervisor to eliminate any possible errors. Try to keep all the participant's related information and documents confidential.

#### **4.1 Patients sociodemographic information**

In the study the number of subjects was eleven with spinal cord injuries. Among the participants there were four female and seven male. The range is minimum age twenty years and maximum sixty five years. There were four tetraplegic spinal cord injury patients and nine paraplegic spinal cord injury patient. Majority participants lived in rural area that were about five and six participants were in urban area. Some reported that they had disability at least three years and there were others with disability for as many as thirty years. Among them majority were unemployed about five participants, three participants are businessman, two participants are service holder, one participants are housewife. All had been educated at least primary school level. In this research the results of the study are discussed in relation to the research questions and objectives of the study. The descriptions of the themes are according to the answer of the participants. Discussion according to the themes are also provided below.

**Table-1: Socio demographic information of the participants**

<b>Partici pants</b>	<b>Age years</b>	<b>in Gender</b>	<b>Marital Status</b>	<b>Occupation</b>	<b>Residential Area</b>	<b>Educational Level</b>	<b>Living with disability</b>
P1	55	M	Married	Service holder	Urban	HSC	18 years
P2	63	M	Married	Unemployed	Urban	Eight	25 years
P3	40	M	Married	Businessmen	Urban	SSC	10years
P4	23	F	Unmarried	Unemployed	Urban	SSC	5years
P5	45	M	Married	Businessmen	Rural	Five	8years
P6	50	M	Married	Businessmen	Rural	Eight	27years
P7	29	F	Unmarried	Service holder	Urban	HSC	10years
P8	60	M	Married	Unemployed	Rural	Five	30years
P9	22	F	Unmarried	Unemployed	Urban	Eight	3years
P10	45	M	Married	Unemployed	Rural	Five	5years
P11	40	F	Married	Housewife	Rural	Five	8years

**Theme-1: Inconvenient accommodation act as a perception of barriers of accessibility in community.**

Category-1: Home related barriers for persons with SCI about accessibility in community.

**Table-2: Home related barriers for persons with SCI about accessibility in community.**

<b>Participants</b>	<b>Inadequate inside space</b>	<b>Narrow doorway</b>	<b>Additional entries, steps or ramps</b>
P1			✓
P2	✓	✓	
P3	✓	✓	✓
P4			✓
P5	✓	✓	
P6		✓	
P7	✓		
P8			✓
P9		✓	
P10	✓	✓	
P11			✓
Total=11	5	6	5

Among eleven participants, majority of participants said that, narrow doorway are the major problem they in accommodation. Some participants said that, Inadequate inside space are also biggest problem in accessibility of community. Out of them said that, additional stairs and steps are key problems in accessibility in community they face.

**Theme-2: Limited scope in toilet remark as a perception of barriers of accessibility in community.**

Catagort-2: Toilet related barriers for persons with SCI about accessibility in community.

**Table-3: Toilet related barriers for persons with SCI about accessibility in community.**

<b>Participants</b>	<b>Asian toilet</b>	<b>High commode</b>	<b>Unhandy accessories</b>	<b>Insufficient space to turn</b>	<b>Modified commode</b>
P1		✓			
P2	✓		✓	✓	
P3				✓	✓
P4	✓		✓	✓	
P5	✓		✓	✓	
P6	✓		✓	✓	
P7	✓			✓	
P8				✓	✓
P9		✓	✓		
P10				✓	✓
P11	✓			✓	
Total=11	6	2	5	9	3

Among eleven participants, nine participants said that, insufficient space to turn wheel chair in toilet are the vital problem as barriers in accessibility of community. Six participants are facing problem when used Asian toilet among them only two participants are used accessible high commode. Five participants said that unhandy accessories in toilet are one of the major problem. Three participants said that modified commode are also as barriers in accessibility of community.



**Theme-3: Unadaptable kitchenette act as a perception of barriers of accessibility in community.**

Category-3: Kitchen related barriers for persons with SCI about accessibility in community.

**Table-4: Kitchen related barriers for persons with SCI about accessibility in community.**

<b>Participants</b>	<b>Unadaptable stove</b>	<b>Copping, cleaning</b>	<b>Higher sink</b>	<b>Out reached shelf</b>	<b>Chance to burn</b>
P1			✓	✓	
P2					✓
P3	✓		✓	✓	
P4	✓	✓	✓	✓	
P5	✓				✓
P6	✓	✓	✓	✓	✓
P7	✓	✓		✓	
P8	✓				
P9	✓		✓	✓	
P10	✓				
P11	✓	✓		✓	
Total= 11	9	4	5	7	3

Among eleven participants, nine participants said that unadaptable stove are the chief problem as barriers in accessibility of community. Seven participants said that out reached shelf are also a serious problem in kitchen. Five participants remarked that higher sink is also a problem for them. Among them four and three participants mentioned that chopping, cleaning and chance to burn is also a major problem in kitchen as barriers in community.

**Theme-4: Exterior built and faulty construction impact on environment as a perception of barriers of accessibility in community.**

Category-4: Environmental issues barriers for persons with SCI about accessibility in community.

**Table-5: Environmental issues barriers for persons with SCI about accessibility in community.**

<b>Participants</b>	<b>Road</b> (Narrow sidewalk, paving stone and obstacles, risk of tipping over)	<b>Ramp</b> (Absence of ramp at the plinth level)	<b>Poor construction</b> (Brick steps, Raw road, muddy and slippery road)	<b>Weather</b> (Rainy season)	<b>Social communication</b> (Harder to go shop or neighbor's house)	<b>Made concrete ramp at own cost</b>
P1	✓					✓
P2	✓		✓	✓	✓	✓
P3	✓	✓	✓	✓		
P4		✓	✓	✓	✓	
P5	✓	✓	✓			
P6	✓		✓			
P7		✓			✓	
P8	✓		✓	✓		✓
P9	✓	✓			✓	
P10	✓	✓	✓	✓		
P11	✓		✓		✓	
<b>Total=11</b>	<b>9</b>	<b>6</b>	<b>8</b>	<b>5</b>	<b>5</b>	<b>3</b>

Among eleven participants nine participants said that inaccessible road like narrow sidewalk, paving stone and obstacles, risk of tipping over are the vital factors are the barriers for persons with spinal cord injury in community. Eight participants said that brick steps, raw road, muddy and slippery road are also the vital factors as barriers in community. Six participants said that absence of the ramp at the plinth level are the great barriers in community participation. Harder to go shop or neighbor's house and Rainy season are also serious barriers in community. Among them three participants made concrete ramp at their own cost.

**Theme-5: Stigmatized social attitude influenced on social participation as a perception of barriers of accessibility in community.**

Category-5: Social participation related barriers for persons with SCI about accessibility in community.

**Table-6: Social participation related barriers for persons with SCI about accessibility in community.**

<b>Participants</b>	<b>Helplessness and dependence</b>	<b>Negligence and Ignorance</b>	<b>Negative criticism</b>	<b>Adversely affected motivation and confidence</b>	<b>Negative belief attitude</b>	<b>social and</b>
P1		✓	✓			
P2	✓	✓		✓	✓	
P3	✓	✓	✓			
P4		✓		✓	✓	
P5	✓	✓	✓		✓	
P6	✓	✓				
P7			✓			✓
P8		✓	✓			
P9	✓		✓			✓
P10		✓				
P11	✓	✓	✓	✓	✓	✓
Total=11	6	9	7	3	6	

Among eleven participants, major of the participants said that, negligence and ignorance is the main barriers in social participation. Seven participants said that negative criticism is one of the key problem in social participation. Six participants mentioned that, helplessness

and dependence is the biggest social perception in community participation. Among them six participation said that, negative social belief and attitude also the barrier in community. Three participants remarked that, social barriers also adversely affected motivation and confidence as a perception of barriers of accessibility in community.

**Theme-6: Interruption in participation in spiritual and cultural activities as a perception of barriers of accessibility in community.**

Category-6: Spiritual and cultural participation related barriers for persons with SCI about accessibility in community.

**Table-7: Spiritual and cultural participation related barriers for persons with SCI about accessibility in community.**

Participants	Inaccessible Religious place	Isolated in Meeting, Assembly	Inaccessible Neighbor house	Inadequate Leisure and recreation
P1				✓
P2			✓	
P3	✓	✓		
P4			✓	✓
P5	✓	✓	✓	✓
P6	✓		✓	
P7			✓	✓
P8	✓	✓		
P9			✓	
P10	✓	✓		
P11			✓	
Total=11	5	4	7	4

Among eleven participants most of the participants said that, inaccessible neighbor house is the main barrier in participation in social and cultural activities. Five participants mentioned that inaccessible religious place also a major barrier in spiritual and cultural activities. Among them four participants said that isolated in meeting and assembly, inadequate leisure and recreation also spiritual and cultural participation related barriers for persons with SCI about accessibility in community.

**Theme-7: Family support and social relationship act as a facilitator as a perception accessibility in community.**

Category-7: Family support and social relationship related facilitator for persons with SCI about accessibility in community.

**Table-8: Family support and social relationship related facilitator for persons with SCI about accessibility in community.**

<b>Participants</b>	<b>Personal care provider</b>	<b>Family support</b>	<b>Friends, neighbor and community support</b>
P1	✓	✓	✓
P2	✓	✓	✓
P3	✓		
P4		✓	
P5	✓	✓	
P6	✓		
P7		✓	
P8		✓	
P9		✓	
P10	✓		
P11		✓	
Total=11	6	8	2

Among eleven participants, eight participants remarked that family support plays an important role in facilitator as a perception of accessibility in community. Six participants mentioned that, personal care provider also a chief facilitator in community participation among person with SCI. two participants said that, friends, neighbor and community support also a major facilitator for persons with SCI about accessibility in community.

In this chapter the results of the study are discussed in relation to the research questions and objectives of the study. The discussion focus on barriers in accessibility of community participation of spinal cord injury patients. By the content analysis different categories are found under which different options are expressed by different codes. Seven major categories found under which seven themes were emerged. This part is carried out on the basis of analysis of acquired data and its relevance with other published literature related to the study.

**Summary of theme that emerged from data analysis:**

**Theme-1: Inconvenient accommodation act as perception of barriers of accessibility in community.**

Home related barriers in community after following spinal cord injury act as a greatest problem in community participation. Many houses in our country are not convenient for wheel chair users. In Bangladesh, both urban and rural areas it is difficult to access the house with wheelchair due to additional entries, concrete steps etc.

One participant mentioned that- *“In most places I can’t get into because they have two or three inches steps or additional stairs and I always need someone who push my chair from behind to go up that steps.”*

Above participants, majority of participants said that, narrow doorway are the major problem they in accommodation. Some participants said that, Inadequate inside space are also biggest problem in accessibility of community. Out of them said that, *“additional stairs and steps are key problems in accessibility in community they face.”*

After spinal cord injury, accessible home environment is an important aspect in everyday life. A recent report from the Swedish government has shown that environmental barriers



act as objectively observable factors are common in the ordinary housing stock overall. Most of the participants considered the lack of accessibility in their homes as an obstacle to participation in community (Schulze et al., 2014).

Another participant said that- *“In my house where I’m living right now, there are no enough space to turn the wheel chair or move around. So, I can’t enter some rooms. But it is difficult to remodel my house again now.”*

So, we can say that the structure of the house act as a barrier for their mobility in community. In our country, the basic scenario of the slum area most of the house are congested to each other. For their low economic status each family has only one room that is used for multifunctional household activities. Which is extremely confined and inadequate for wheel chair user for their mobility.

One participant remarked that- *“I live in a ground floor. I order to entrance my house I need to go through a narrow corridor”*

Other participant said that- *“Basically not every house in our country is well designed for disable people. There are no enough space in my house to turn the wheel chair or move around”*

Now a days some places in city area accessibility is typically good than rural. Some of them built it conveniently at their own cost. People with SCI require just an accessible front door through which they can pass. One participant said that- *“I made ramp with my own cost. I made ramp everywhere (Toilet, kitchen, inside the house). Even I made ramp at my country house.”*

Norin et al., stated that, Physical accessibility in many communities has improved dramatically in the past twenty years. The transition from acute rehabilitation to home is especially critical as they attempt to resume participation in the community. Around 1.8 million disabled people in England are currently struggling to find appropriate housing, with only less than one in ten properties being available that are fully accessible. In Scotland, the number of people in unsuitable housing is set to increase by 80% in the next 6 years. Affordable new homes are often too small for wheelchair users.

It is estimated from the study that, modifying an individual's home is one of the most important steps to assist someone in remaining in their home if they have physical limitations. Many disabled people and their families are reporting that home accommodation are not accessible for their needs.

## **Theme-2: Limited access in toilet act as perception of barriers of accessibility in community.**

Person with spinal cord injury using wheel chair would have to experience many disadvantage or barrier in toilet. From the participants, a clear understanding of individuals with disabilities that access in toilet is important part of everyday life. Though Bangladesh is a low economic country, here a large amount of community use squat toilets. In countryside it is very difficult to get into a squat toilet with wheelchair because the only toilet they have use, which is just hole above a pit.

One participant said that, *“I used Asian type of toilet. So, it is too difficult for me that there is not enough space to move wheelchair inside the toilet. The Door is too tight and narrow. Moreover using water and tissue after toileting is more difficult for me because there are not enough space to do that so I like to bath for cleaning purposes after each toileting into the water point where I get adequate space.”*

There are limited space in toilet also a major problem for wheelchair user. For that reason, biggest wheel chair cannot drive in toilet also cannot spin around. Lack of space career has not enough space to move around them. Toilet accessories are also out of hand. So, they are not easy to use.

Another participant said that, *“. It is too difficult for me using toilet. In the bathroom, when I take a shower, there is nothing to hold on to. I get scared when I go in there. I have a chair so I can use that, but the bathroom is very unsafe for people like us, sometimes I scared to fall.”*

In rural area female wheel chair user face so much difficult. Absence of accessible toilet is not a little problem. It is a major worry. For rural respondents piped water was not available. Thus physical barriers associated with distance and the need to carry water emerged as important concerns for disabled people.

One female participants mentioned that, *“The way get water and use the toilet makes me feel different. Here is limited water. That means I cannot wash my body and clothes properly so this is a major challenge. Sometimes it took long wait to go in toilet for bathing and get wet my clothes.”*

Another female participant explained that, *“sometimes I didn’t like bathing either but was often forced to by my carer. I feel unhappy in the toilet and the bathroom because they were smelly places and they made me feel embarrassed because I have to use them differently. I always tensed about my privacy.”*

From the reported of the above, we can understand that, managing toileting activities is an essential but very difficult daily living task for person with wheelchair user. Everyone would like to maintain independence, privacy and dignity. There are many elements to consider including access to toilet facilities. Toilet accessibility is a major barrier for wheel chair user person for community participation.

### **Theme-3: Unadaptable kitchenette as a perception of barriers of accessibility in community.**

The kitchen is the most important place in the house for daily basis. For a wheel chair user kitchen presented more problems than any other room or area in the house. Though, in feminist society like Bangladesh, domestic work is usually done by women. Following this traditional roles, household responsibilities and cares are mainly look after by women. Cooking with a wheel chair is a daunting task. Unadaptable kitchen is the major barrier in community.

One participant said that, *“I need to use manual wheelchair all the time, so it is difficult to get in the kitchen and cook food. Because the drawers and boards are not adjustable. Also, I had a surgery on my back, and I was advised not to do any downward bending activities.”*

Many problems related to difficulty for a female using a wheelchair in the kitchen. One woman had difficulty with her wheelchair to turn on the gas stove or take food out from the stove. Another woman used a gas stove. Because she had to reach behind the burners, her head came dangerously close to the burners. It is important for wheelchair users to have adequate counter space to keep frequently used items.

Another participant said that, *“I didn’t cook usually for my family. I scared to burn. Sometimes I get frustrated for that.”*

In rural are, people use low wood burning ovens. From which a lot of smoke comes out. Inadequate ventilation in kitchen that causes chest complication. On the other side, cooking can present challenges for manual wheelchair user, they need low trolley. But there are some of the common issues include limitations in standing, reaching, or using one side of the body.

One participant mentioned that, *“I’ve two kitchens. One of them are with gas and others are to cook with wood. That’s why the kitchens are separate. And I can use the gas stove. I have made everything suitable for me so that now I can cook, wash my face at the basin, can go to the toilet easily by myself.”*

Cleaning is the important part of cooking. Higher sink and out reached shelf also a barrier in kitchenette activities. One participant said that, *‘In a wheelchair, it is almost impossible for cleaning to get up close enough to the sink because my feet will be blocked by the cabinets below. The sink that doesn’t provides enough space beneath wheelchair accessibility will allow users to access the sink. Knee clearance for using a sink also needs to clean.’*

#### **Theme-4: Exterior built and faulty construction impact on environment as a perception of barriers of accessibility in community.**

Environmental barrier in community and its surroundings traditionally been viewed as an important barrier for spinal cord injury person with wheel chair. Participants faced difficulties with accessibility in both rural and urban environments. It includes roads, ramp, poor construction, weather, social communication. Weather has a great impact on the environmental barrier. In rainy season, roads are become muddy and slippery in rural area and water flows through city streets.

One participant said that, *“During rainy season level of my suffering is limitless. Most of the time water assemblage in street like a pool. I need other people’s help for push up my wheel chair from behind. Because the roads are muddy and slippery. Sometimes I face difficulty to move the chair alone the path. I can’t go outside in this bad condition.”*

Moreover, in many area roads are unwelcoming for people in a wheelchair. People with wheelchair do not have easy access to move around by using the walkway. The reason for the absence of proper walkway are the illegal parking on the footpath, uneven surfaces, signboards, garbage on sidewalks.

One participant said that, *“sometimes I used to go in the streets and off the sidewalk and go to streets and that are one of the more dangerous things I’ve found since being in a wheelchair. Normally I go and crossing streets slower than others, I feel scared.”*

Even roads are not designed well, without proper maintenance, these became unfriendly to people with wheel chair user. The surface is often uneven with broken and several potholes.

Trash, construction materials and street hawkers occupy the precious space, which makes sidewalks for wheel chair user inaccessible even may cause falls or injury.

Another participant remarked that, *“Sometimes I face extreme difficulty to move the chair alone in street paths and cross the road due to poorly construction and steep crossover. In rainy season water gets up in the streets and roads are become muddy and slippery. So, it becomes more difficult to move my wheelchair”*

Many buildings in city area do not have ramps for wheel chair user. Too much stair in everywhere. They can't go super shop or medicine corner if they need. That are the major barrier for social communication. Inappropriately installed ramps are the major deficiencies. Some participant reported that they made ramps for their own cost.

One participant said that, *“In the house where I'm living right now, I made ramp with my own cost. I made ramp everywhere (Toilet, kitchen, inside the house). Even I made ramp at my country house.”*

Harris et al., 2015 estimated that, Wheelchair users routinely encounter difficulties while traveling in their communities, even on routes that are considered accessible under the Americans with Disabilities Act Accessibility Guidelines (ADAAG). For their point of view, we can say that, environmental barrier act as major problem in community participation. It seems that inaccessibility to public spaces hinders socialization of individuals with SCI, decreases the rate of social communication, and complicates coping with a disability.

### **Theme-5: Stigmatized social attitude influenced on social participation as a perception of barriers of accessibility in community.**

Community attitudes, support and acceptance were also another factor identified as a barrier to coping with SCI. Stigmatized social attitude remained a major concern for participants, affecting the way in which they were able to access their support services. It is a major barrier for a wheel chair user in community participation. They find limitation to go out. They always need other people's help to go anywhere with wheelchair. So that, many of them don't go out of the house so long.

One participant said that, *"I like to do all kind of social activities. But sometimes I face ignorance and negligence. I always need someone help but I need to wait a long time."*

Lack of attention and not being listened their words make some participants disappointed. That resulted in feeling them unimportant and exclusion. This kind of social attitude adversely affected their motivation and confidence.

Another participant reported that, *"When Normal people can deliver their speech in public stage, I can't. People don't appraise my word. Even they laughed at me. My friend don't care what I say."*

In our society, women with spinal cord injury have different life experiences than man due to pattern of their social position. Women with disabilities face multiple discriminations and disadvantage. They face a negative attitude not only from society but also even from their family members. They marked as a total burden sometimes facing physical assault, some of them getting divorced. Some of them getting despise, because they are seen as unattractive in society's eye and renders the woman ineligible for marriage. Taub et al., 2009 find on a study that, physical appearance of a disable person adversely affected her social life.

One participant said that, *"my husband left me after my injury. He spend a lot of money on my medical treatment. I can't work like as before, he stared to hate me.it hurts me."*

Spinal cord injury creates a sense of weakness in the patient's in terms of the security of the marital relationship. Partners have also a stronger fear of separation and a higher sense

of dependency as a result of spinal cord injury. Marriage and social support are inversely proportional to each other. SCI represent to them as a social burden to their partners. (Weitzenkamp et al., 1997).

Another participant said that, *“I struggled really hard to deny my disabilities. I would avoid even another disabled person that came around, that I’d be associated with them. I thought I could blend in better around other people. They reacted differently to me than when it was out front. I just feel like I’m not the typical girl that everybody goes after.”*

Ignorance and false beliefs surrounding disability, compounded with a negative and insulting attitude of the community act as a major barriers. If the attitude of people towards a wheelchair user is poor, it could lead to barriers. On the other hand, positive attitudes will create the enabling environment for wheelchair user to feel belonged and accepted.

One participant mentioned that, *“In the country side, we (the disable person) are neglected every time. For example, there was held an audience chamber. At that time though I talked legally, they avoid me. They don’t want to judge my opinion. Sometimes we tried, applied to the chairman for a helping hand for the disabled person. There is no ramp at the chairman office. So, I applied for one and they made it.”*

In rural area, participant face some misbelief about their disability. Some of blame that, disability was their fate. People often criticism that disability is a curse or due to sinning in past. Some people said that, *“When they see us at the streets, they regard us as pathetic and doomed.”* This traditional beliefs also increase barrier in participation in community.

Newman al el., 2010 reported that, Existence of barriers in the environment gives rise to a sense of discrimination in people with SCI, prevents their social participation, limits their choices and foils their attempts to lead an independent life and the ability to care for themselves.

Above their estimated, we can say that Social discrimination and negative criticism on people with wheelchair user spinal cord injury person in community is very common. They are often looked at with over sympathy or neglect. They are mistreated and exploited in all



spheres of social life. They are relatively invisible in social functions and gatherings. In this social attitude act as a barrier in community participation.

### **Theme-6: Interruption in participation in spiritual and cultural activities as a perception of barriers of accessibility in community.**

Interruption in social and cultural participation activities also a major barrier in community participation. In our country, many religious places are not accessible for disable person. There are no ramps so that a people with spinal cord injury can go not there with their wheel chair.

One participant said that, *“When I need to go Mosque for prayers I need help other people from behind. I feel lucky that I got help and support all the time when I face any difficulty.”*

Spirituality was strongly linked to enhanced quality of life, life satisfaction and resilience among SCI people. Spirituality is a key factor after adjustment of SCI. Spirituality may also include the process of finding significance and purpose through the natural world constantly, attaching with others, and finding power within oneself (Jones et al., 2018).

Some of they become isolated from general meeting because of their disability. Carpenter et al., 2007 estimated in her research that spinal cord injury person experienced social and physical activity limitation. According to ICF the manufacture and activities of spinal cord injury persons are blurred.

One participant mentioned that, *“When I need to go Mosque for prayers I need help other people from behind. I feel lucky that I got help and support all the time when I face any difficulty. Whenever they saw me in the street, they came and asked me whether I need any help.”*

Due to poor construction and inaccessible equipment their suffering are limitless not only hot temperature but also in rainy season. They have to pray outside sometimes in heat and sun exposure because it is difficult to carry an umbrella while using a wheelchair.

Another participant said that, *“When I had my prayer wetting in the rain, they lifted me up to the mosque and lifted my down. A person like me is needed whole time to ride a wheel chair.”*

On the other hand, participants with spinal cord injury, in queenland, experienced different life style and individual challenges in daily life activities. For their different environmental status heat and rain causes major effect on their community participation. Because of it they got frustration (Carr et al., 2016).

One participation explained that, *“Sometimes I feel life would become much better if people in our society understand what we go through, like after my injury I didn’t get enough attention from my friends now I feel like I’m left alone. I have been isolated, even they don’t need to contact with me. It is very frustrating.”*

According to Taub et al., 2009 finding, the maintenance of spiritual and cultural activities with friends and neighbor also a major barrier in community participation. Some of them found that they have been isolated day-by-day. Their relatives and friends no longer visited or invited them in any occasion. On the opposite, inadequate accessibility and their physical inability spontaneously restricted them to go or visit somewhere.

From their speech, it seems clear that, social isolation and ignorance creates adverse reaction in their mental health. That interruption in participation in spiritual and cultural activities as a barrier in community participation.

## **Theme-7: Family support and social relationship act as a facilitator as a perception accessibility in community.**

Family plays a fundamental source of supports and cares for people with disability. Family and social support emphasizes relationship in between personal care provider and surrounding community. Without their support it is quite difficult to sustain their lives. Person with wheelchair user always need not only family support but also available community resources to oppose these challenges. Social support also creates mutual obligations in which an individual feels.

One participant said that, *“My family has always been with me through the ups and downs. They treated me better. It’s hard for person like me to survive without family’s support. Sometimes I feel life would become much better if people in our society understand what we go through.”*

Grossman et al., 2016 estimated that, family members are essential elements and many times it is unpaid source of support in the United States for people with disabilities cooperating with tasks that promote community participation. Social support is an important facilitator in community participation to assist individuals.

Personal care provider plays as an important role in family and social relationship act a facilitator in community participation. They are normally close family members who had took the total care giver responsibilities mainly unpaid women, wives or sisters (Barclay et al., 2015).

Another participant mentioned that, *“my family members are my lifesaver. I can’t pass a single day without support of my family member. They continuous care about my physical condition. They provide any kind of facilities whenever I need. We, the disable person, need more support from our family it may be psychological or cultural aspect.”*

From their point of view, there is a clear concept that, family support and social relationship is a major framework of community participation as a wheelchair person. It is also acknowledge that family and social relationship act as a facilitator in community participation of individuals.

## **Limitation**

This is a qualitative type of study purposive sampling was used to collect data from participants. The validity and reliability of the semi-structured questionnaire used in this study was not tested. In-depth interview was required to gain information from participants. Due to lack of interviewing skills it was not possible to collect data from participants thorough. Besides, participants have given different information rather than related information to study when audio records was used. Due to time limitation small area are selected for this study.

**6.1 Conclusion**

This study demonstrate factors that, from wheel chair user spinal cord injury patient's perspective about their accessibility in community to struggle with disability. Participants explains their biography about their obstacles, facilities, existence and current conditions in society to attain an ideal level of adaptation. According to the participants, results indicates that inconvenient accommodation, environmental barriers, stigmatized social attitude act as an major barrier in community participation for wheel chair users. This results are comparable with those reported by, Sekaran et al., 2010, who reported physical environment persist as a major barrier and inaccessible for people with disabilities. As an environmental barrier wheel chair user spinal cord injury person routinely face barrier in narrow sidewalk, slippery road, absence of road and ramp. This result much similar to, Botticello et al., 2018, who reported that, environmental factor plays an important role to the experience of disability. A valuable perception is gained by individuals living with disability that family and social support contribute them as a facilitator in community participation. This current result resembling with previous result that identified family and social support reflex them as a lifeline in social participation by people with spinal cord injury. On the other hand, the basic scenario in our country, most of the people still are not aware about physical and environmental accessibility, social stigma, acceptance of disable person. From the participants of individuals, they perceived that awareness rising is the major factor to aware people about their disability. Rising awareness from urban to rural societies can concern them about accessibility of wheel chair user disable person to participant their community life satisfactorily.

## **6.2 Recommendation**

It is recommended to do further research on a large group of people in qualitative approach to find out the economical, and health related barriers faced spinal cord injury person involving in community participation and also find out the overcoming policy of barriers in community participation.

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## Appendix

### Verbal Consent Statement

(Please read out to the participants)

Assalamualaikum / Namasker,

My name is Nishat Tasnim, I am conducting this study for 4<sup>th</sup> professional B.Sc. in physiotherapy project study dissertation titled, **“Perception about accessibility in community among wheel chair user person with spinal cord injury”**. By this I would like to know the perception about accessibility in community among wheel chair user person with spinal cord injury. Now I want to ask some personal and accessibility in community related question. This will take approximately 20-30 minutes.

I would like to inform you that this is a purely academic study and will not be used for any other purpose. This researcher is not directly related with this area (Spinal cord injury). So, your participation in the research will have no impact on your life. All information provided by you will be treated as confidential and in event of any report or publication it will be ensured that the source of information remains anonymous.

Your participation in this study is voluntary and you may withdraw yourself at any time during this study without any negative consequences. You also have the right not to answer a particular question during interview.

If you have any query about the study or your right as a participants, you may contact with me and/or my supervisor, Farjana Sharmin, Lecturer BHPI, Junior consultant & OPD incharge, Department of physiotherapy, BHPI, Savar, Dhaka-1343.

Do you have any questions before I start? Yes / No

So, Consent taken from participants. Yes.....

Signature of the participant: ..... Date: .....

Signature of the interviewer: ..... Date: .....

## Questionnaires (English)

1. How much you know about your injury?
2. What is your idea about accessibility? Please describe?
3.
  - a) Are the entrance door of your house wide enough to be accessible?
  - b) Are there sufficient space in your house to manipulate a wheelchair between two sets of doors?
  - c) Are there accessible space inside your bathroom with all fixtures and fittings being within easy reach?
  - d) If the problem present, what kind of obstacles you might face?
4.
  - a) How are the roads around your house? Are they easily accessible for you to move around in your community for your daily basis?
  - b) If the problem present, what kind of obstacle you might face?
  - c) Do you think this accessible is important? Why?
5.
  - a) Do you face any challenge in participating social activity (meeting, political, cultural)?
  - b) If the problem present, what kind of challenge you might face?
6.
  - a) Do you get any help and support from your family member whenever you face any obstacle?
  - b) If yes, what kind of help did you get from them?
7. What do you think? What kind of modification can get rid from those problem?



মৌখিক অনুমতিপত্র

( অংশগ্রহনকারীকে পড়ে শোনাতে হবে )

আসসালামু আলাইকুম / নমস্কার,

আমি নিশাত তাসনিম, আমি এই গবেষণা প্রকল্পটি বাংলাদেশ হেলথ প্রফেশন ইনস্টিটিউট ( বিএইচপিআই)- এ পরিচালনা করছি যা আমার ৪র্থ বর্ষ বিএসসি ইন ফিজিওথেরাপি কোর্সের অধিভুক্ত। আমার গবেষণার নাম হলো- “মেরুরজ্জুতে আঘাতপ্রাপ্ত হুইলচেয়ার ব্যবহারকারী ব্যক্তিদের মধ্যে সম্প্রদায়ে সহজগম্যতা সম্পর্কে ধারণা।” এর মাধ্যমে আমি মেরুরজ্জুতে আঘাতপ্রাপ্ত হুইলচেয়ার ব্যবহারকারী ব্যক্তিদের মধ্যর সম্প্রদায়ে সহজগম্যতার ধারণা সম্পর্কে জানতে চাই। আমি এখন আপনাকে কিছু ব্যক্তিগত এবং সম্প্রদায়ে সহজগম্যতা সম্পর্কে আনুষঙ্গিক প্রশ্ন করতে চাই। এতে

আমি আপনাকে অবগত করছি যে, এটা আমার অধ্যয়নের অংশ এবং যা অন্য কোন উদ্দেশ্যে ব্যবহৃত হবে না। এই গবেষণায় আপনার অংশগ্রহন বর্তমান জীবনে কোন প্রভাব ফেলবে না। আপনি যে সব তথ্য প্রদান করবেন তার গোপনীয়তা বজায় থাকবে।

এই অধ্যয়নে আপনার অংশগ্রহন স্বেচ্ছাপ্রণোদিত এবং আপনি যে কোন সময় এই অধ্যয়ন থেকে কোন নেতিবাচক ফলাফল ছাড়াই নিজেকে প্রত্যাহার করতে পারেন। এই অধ্যয়নে অংশগ্রহনকারী হিসাবে যদি আপনার কোন প্রশ্ন থাকে তাহলে আপনি আমাকে অথবা আমার সুপারভাইজার, ফারজানা শারমিন, লেকচারার বিএইচপিআই, জুনিয়র কনসালটেন্ট এন্ড ওপিটি ইনচার্জ, ফিজিওথেরাপি বিভাগ, বিএইচপিআই, সিআরপি, সাভার, ঢাকা- ১৩৪৩ তে যোগাযোগ করতে পারেন।

সাক্ষাৎকার শুরু করার আগে কি আপনার কোন প্রশ্ন আছে?

সুতরাং আমি আপনার অনুমতিতে এই সাক্ষাৎকার শুরু করতে পারি?

হ্যাঁ..... না.....

১। অংশগ্রহনকারীর স্বাক্ষর..... তারিখ.....

২। উপাত্ত সংগ্রহকারীর স্বাক্ষর..... তারিখ.....

## প্রশ্নাবলী (বাংলা)

- ১। আপনি আপনার নিজের সম্পর্কে কিছু বলুন।
- ২। আপনি আপনার আঘাত সম্পর্কে বিস্তারিত বলুন। ( কিভাবে / কখন /বর্তমানে কি অবস্থা)
- ৩। আপনার বাড়ির প্রবেশপথ সম্পর্কে বিস্তারিত বলুন। ( সিঁড়ি , সহজগম্যতা, প্রশস্ততা)
- ৪। আপনার দৈনন্দিন জীবনে প্রবেশ পথে হুইলচেয়ার নিয়ে যে বাঁধার সম্মুখীন হোন সেগুলো সম্পর্কে বিস্তারিত বলুন।
- ৫। আপনার বাড়ীর ভিতরে হুইলচেয়ার নিয়ে চলাফেরার জন্য কি যথেষ্ট জায়গা আছে?
- ৬। আপনি যখন হুইলচেয়ার নিয়ে বাথ্রুমে প্রবেশ করেন তখন বাথ্রুমের প্রয়োজনীয় সামগ্রী কি আপনার সুবিধাজনক হাতের নাগালে থাকে?
- ৭। আপনার বাড়ির রান্নাঘর আপনার ব্যবহারের জন্য কতটুকু সুবিধাজনক সে সম্পর্কে বিস্তারিত বলুন।
- ৮। এই বাঁধা গুলো থেকে উত্তোরনের জন্য কি করা যেতে পারে বলে আপনি মনে করেন।
- ৯। আপনার বাড়ীর আশেপাশের বা আপনার এলাকার রাস্তা হুইলচেয়ার নিয়ে চলাচলের জন্য কতটুকু সুবিধাজনক বলে মনে করেন? সেগুলো সম্পর্কে বিস্তারিত বলুন।
- ১০। আপনি যখন হুইলচেয়ার নিয়ে আপনার বাড়ীর আশেপাশের বা এলাকার রাস্তায় চলাফেরা করেন তখন যে অসুবিধাগুলোর সম্মুখীন হোন সেগুলো নিয়ে বিস্তারিত বলুন।
- ১১। আপনি যখন কোন সামাজিক কাজকর্মে অংশগ্রহন করতে চান ( যেমনঃ নামাজ, ধর্মীয় অনুষ্ঠান, রাজনৈতিক সভা) তখন যে বাধার সম্মুখীন হোন সেগুলো নিয়ে বিস্তারিত বলুন।
- ১২। আপনি এই যে প্রতিনিয়ত বিভিন্ন ধরনের বাঁধার সম্মুখীন হচ্ছেন এই সমস্যাগুলো সমাধানে আপনার পরিবার বা আশেপাশের লোকজনের কাছ থেকে কোন ধরনের সাহায্য পান? বিস্তারিত বলুন।
- ১৩। আপনার মতে এই বাঁধা গুলো উত্তোরনের কি করা যেতে পারে তা সম্বন্ধে বিস্তারিত বলুন।

**Permission letter**

April 20, 2019

The Head of the Department,

Department of physiotherapy,

Bangladesh Health Profession Institute (BHPI),

CRP, Chapain, Savar, Dhaka-1343.

Dear Moslem Bhai,  
Please assist her by giving  
10 people e sci details  
Salim Rahman 20/4/19

**SALIM RAHMAN**  
Assistant Manager  
Rehabilitation Wing  
CRP, Bangladesh, Savar, Dhaka-1343

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

Dear Sir,

With due respect and humble submission to state that, I am Nishat Tasnim, student of 4<sup>th</sup> professional B.Sc. in physiotherapy at Bangladesh Health Professions Institute (BHPI). The ethical board of BHPI has approved my research project entitled on "Perception about accessibility in community among wheel chair user person with spinal cord injury". To conduct this research, I want to collect data from the community in patient with spinal cord injury who completed their rehabilitation treatment from CRP. So, I need permission for data collection from the community. I would like to assure that anything of my study will not be harmful for the participants.

I, therefore, pray and hope that you would be kind enough to grant my application and oblige thereby.

Sincerely Yours,

Nishat Tasnim

Nishat Tasnim  
Student of 4<sup>th</sup> professional B.Sc. in physiotherapy  
Roll no: 32, Session: 2014-2015  
Bangladesh Health Profession Institute (BHPI)  
(An academic institute of CRP)  
CRP, Chapain, Savar, Dhaka-1343.

Allowed  
20-04-19

**Prof. Md. Obaidul Haque**  
Head, Department of Physiotherapy  
BHPI, CRP, Savar, Dhaka-1343

Approved  
Mohammad Baitullah  
Associate Professor & Head  
Physiotherapy Dept., CRP  
CP, Chapain, Savar, Dhaka-1343

Rumana  
**FARJANA SHARMA**  
Junior Consultant and OPD In-charge  
Physiotherapy Department  
CRP, Savar, Dhaka.



বাংলাদেশ হেল্থ প্রফেশন্স ইনস্টিটিউট (বিএইচপিআই)  
BANGLADESH HEALTH PROFESSIONS INSTITUTE (BHPI)  
(The Academic Institute of CRP)  
CRP-Chapain, Savar, Dhaka-1343. Tel: 02-7745464-5, 7741404

Ref: CRP-BHPI/IRB/09/19/1333

Date: 17/09/2019

To  
Nishat Tasnaim  
B.Sc. in Physiotherapy  
Session: 2014-2015, Student ID:112140246  
BHPI, CRP, Savar, Dhaka-1343, Bangladesh.

**Subject:** Approval of the thesis proposal “**Perception about accessibility in the community among wheelchair user spinal cord injury persons**” by ethics committee.

Dear Nishat Tasnaim,

Congratulations,

The Institutional Review Board (IRB) of BHPI has reviewed the above-mentioned dissertation, with you, as the Principal investigator. The following documents have been reviewed and approved:

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

The purpose of this study is to find out perception about accessibility in the community among wheelchair user spinal cord injury persons. A semi-structured questionnaire will be used and the participant may take 10 to 15 minutes to answer the questionnaire. There is no likelihood of any harm to the participants. Data collectors will receive informed consents from all participants. Any data collected will be kept confidential. The members of the Ethics committee have approved the study to be conducted in the presented form at the meeting held at 10 AM on 11<sup>th</sup> August 2018 at BHPI.

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

Best regards,

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