



**An Evaluation of Spinal Cord Injury Patients at the end of five years after  
discharge from CRP**

Md. Akhlasur Rahman

Part-II, M.Sc in Rehabilitation Science

BHPI, CRP, Savar, Dhaka-1343

Session: 2016-2017

DU Registration No.: 4009

Submitted in Partial Fulfillment of the Requirements for the Degree of M.Sc. in  
Rehabilitation Science June 2018

Bangladesh Health Professions Institute (BHPI)

Medicine Faculty

**University Of Dhaka**

## **SUPERVISOR’S STATEMENT**

As the supervisor of Md. Akhlasur Rahman Thesis work, I certify that I consider his thesis “**An Evaluation of Spinal Cord Injury Patients at the end of five years after discharge from CRP**” to be suitable for examination.

.....

Dr. Mohammad Alamgir Kabir

Professor

Department of Statistics

Jahangirnagar University

Savar, Dhaka – 1342, Bangladesh

(Supervisor)

Date:

We, the undersigned, certify that we have carefully read and recommended to the Faculty of Medicine, University of Dhaka, for acceptance of this thesis entitled “An Evaluation of Spinal Cord Injury Patients at the end of five years after discharge from CRP” submitted by Md. Akhlasur Rahman, for the partial fulfillment of the requirements for the degree of M. Sc. In Rehabilitation Science.

.....  
**Prof. Dr. Alamgir Kabir**  
Professor, Department of Statistics  
Jahangirnagar University, Savar, Dhaka-1343, Bangladesh

.....  
**Md. Habibur Rahman**  
Associate Professor, Department of Physiotherapy  
BHPI, CRP, Savar, Dhaka-1343, Bangladesh

.....  
**Dr Kamal Ahmed**  
Associate Professor, Institute of Health Technology  
Mohakhali, Dhaka-1243, Bangladesh

.....  
**Muhammad MillatHossain**  
Assistant Professor and Co-ordinator  
Department of Rehabilitation Science  
BHPI, CRP, Savar, Dhaka-1343, Bangladesh

**Date of approval:** ....., 2018

## **DECLARATION**

- This work has not previously been accepted in substance for any degree and is not concurrently submitted in candidature for any degree.
- This dissertation is being submitted in partial fulfillment of the requirements for the degree of MSc in Rehabilitation Science.
- This dissertation is the result of my own independent work/investigation, except where otherwise stated. Other sources are acknowledged by giving explicit references.

A Bibliography is appended.

- I confirm that if anything identified in my work that I have done plagiarism or any form of cheating that will directly awarded me fail and I am subject to disciplinary actions of authority.
- I confirm that the electronic copy is identical to the bound copy of the Thesis.

Signature:

Name: Md. Akhlasur Rahman

Date:

## ACKNOWLEDGEMENT

I would like to pay my gratitude to Almighty God who gave me the passion to complete this study. I want to acknowledge my family members who had always inspired me and provide me all necessary supports. I am immensely grateful to my supervisor, supervisor, Professor Dr. Mohammad Alamgir Kabir, Jahangirnagar University for his valuable supervision, guidance and feedback during study period.

I would like to express my deepest gratitude to the CRP (Centre for the Rehabilitation of the Paralyzed) and Bangladesh Health Professions Institute (BHPI), to give me the opportunity to perform this study.

I would also like to thank Head of Medical Services Wing, Medical Services Wing, CRP, Savar, Dhaka for providing all the necessary data. I am thankful to all of my honorable teachers specially Muhammad Millat Hossain, Assistant Professor and Course coordinator, Department of Rehabilitation Science and Nasirul Islam, Associate Professor & Principal (Acting), BHPI, and MD Shofiqul Islam, Assistant Professor, Principal investigator, CIVIC Trial Project, CRP for their valuable suggestions.

Specially, I would like to thank my friend Mohammad Morshedul Quadir, Mahmudul Hassan Al Imam, Samira Anjum, Farjana Touheed for their tremendous support and guideline from the very beginning of my study. And also wants to give thanks Kumar Amitav, for his support and end touch.

I would like to express my gratefulness to the patient and their care giver who gave their valuable time and provided the information, related to my study and helped me to make my work successful.

## **TABLE OF CONTENTS**

	Acknowledgement	iv
	Table of Contents	v-vi
	List of Figures	vii
	List of Tables	Viii
	List of Annexes	ix
	List of Abbreviations	x
	Executive Summary	xi-xii
	<b>CHAPTER I: INTRODUCTION</b>	<b>1-12</b>
1.1	Introduction	1-2
1.1.1	Background	3-5
1.1.2.	In context of developed countries	6
1.1.3	In context of developing countries	7-8
1.1.4	In context of Bangladesh	9-10
1.2	Justification	11-12
1.3	Research question	13
1.4	Operational definition	14

1.5	Outline of thesis	15
	<b>CHAPTER II: LITERATURE REVIEW</b>	16-29
2.1	Introduction	16-24
2.1.1	In context of developed countries	25-26
2.1.2	In context of developing countries	27-28
2.1.3	In context of Bangladesh	29
	<b>CHAPTER III: RESEARCH METHODOLOGY</b>	30-41
3.1	Study objectives	31
3.1.1	General objective	31
3.1.2	Specific objectives	31
3.2	Study design and study Population	32
3.3	Study area and study Period	32
3.4	Sample size and sampling Technique	33
3.5	Inclusion & exclusion criteria	34
3.6	Data collection tools	34
3.7.1	Socio-demographic questionnaire	35
3.8	Data management and analysis	36-37

3.9	Quality control and quality assurance	37
3.10	Ethical Consideration	37
	<b>CHAPTE IV: RESULTS</b>	38-64
4.1	Respondents Socio-demographic characteristics	38-42
4.2	Respondents secondary complication and mortality	43-52
4.3	Responds psychological status and quality of life.	53-56
4.4	Level of Depression	57
4.5	SF-12	58-59
4.6	Mental QoL	60-62
4.7	WHODAS	63-64
	<b>CHAPTER V: DISCUSSION</b>	65-70
	<b>CHAPTER-VI: CONCLUSION &amp; RECOMMENDATION</b>	71-75
6.1	Conclusion	71-72
6.2	Recommendation	73-74
6.3	Strengths and Limitations of the Study	75
6.4	Suggestions for future research	75
	References	76-82



## LIST OF FIGURES

Fig: 4.1.2	Distribution of monthly family income	40
Fig: 4.1.3	Distribution of type of paralysis among the SCI patient	41
Fig: 4.1.4	Mobility status of SCI Patient	42
Fig: 4.2.4	Mortality rate due to secondary complications	52
Fig: 4.5.1	Distribution of domains of Quality of Life	59

## LIST OF TABLES

Table: 4.1.1	Distribute sciodemographic data	39
Table: 4.2.1	Distribution of secondary complications show average point of '0' to '48'	43
Table :4.2.2	Cross tab secondary complication data with socio-demographic data, type of paralysis and mobility status.	46
Table :4.2.3	Average point of Mean of the secondary complication	51
Table :4.3.1	Depression Scale revised versions show average point of Mean of the Secondary complication.	54
Table : 4.3.2	Cross-tab analysis depression scale with socio-demographic data, education type of paralysis and mobility of status.	55
Table : 4.4.1	Distribution of level of depression	57
Table : 4.6.1	Mean and Standard deviation of physical QoL domain scores.	60
Table : 4.6.2	Mean and Standard deviation of mental QoL domain scores	61
Table : 4.6.3	Comparison of Means of Physical and Mental QoL Domain Scores.	62
Table : 4.7.1	Distribution of Community Participation Scale Revised Version.	63
Table: 4.7.2	Distribution of Score Found in the WHODAS Scale.	64

<b>ANNEXES</b>	78-99
Informed Consent (English)	83
Informed consent (Bangla)	84
Questionnaire (English)	85-96
Questionnaire (Bangla)	97-106
Application of permission to Physiotherapy Department	107

## **List of abbreviations**

BHPI	Bangladesh Health Professions Institute
CRP	Centre for the Rehabilitation of the Paralysed
EPUAP	European Pressure Ulcer Advisory Panel
ERB	Ethical Review Board
LMICs	Low- and middle-income countries
NPUAP	National Pressure Ulcer Advisory Panel
NTSCI	Non-Traumatic Spinal Cord Injury
PPPIA	Pan Pacific Pressure Injury Alliance
PUAQ	Pressure Ulcer Attitude Questionnaire
PU	Pressure Ulcers
QOL	Quality of Life
SCI	Spinal Cord Injury
TSCI	Traumatic Spinal Cord Injury
USA	United States of America
UN	United Nation
WHO	World Health Organization

# Executive Summary

## **Background:**

The incidence of spinal cord injury continues to be increasing day by day throughout the world but the incidence rate is higher in low income countries. Life expectancy after SCI is markedly reduced due to secondary complications, severity of injury, social deprivation, and lack of proper rehabilitation. Most common and life threatening secondary complications in resource poor settings are pressure sore, urinary tract infection, contractures, chronic pain, deep vein thrombosis etc.

## **Objective:**

The main objective of the study was to determine current status of person with SCI who had discharged from hospital 5 years ago.

## **Method:**

This was a cohort retrospective observational study of the spinal cord injury patients admitted for rehabilitation at Centre for Rehabilitation of Paralyzed (CRP) in Bangladesh in 2011. Sample size was estimated according to following formula with 95% confidence level, 5% margin of error and a total population of 295 patients, from that sample size was 168. But 50 patients were being interviewed from that by using simple random sampling in the Microsoft Excel Worksheet. Records of all admitted patients with spinal injuries from January 2011 to December 2011 were followed up by phone call and home visits were carried out when needed. Researcher used preforms pretested scale of SCI secondary condition, WHODAS scale, SF-12 scale, CESDE-R scale and questionnaire about his activities.

**Result:**

Among 50 participants, majority of them were male (88%, n=44) and only 12% were female. Mobility assessment found that majority of the cases were wheelchair user (64%, n=32) and (36%, n=18). Out of 45 patients we found that Bowel dysfunction (64.4%) was the most common complication, followed by spasticity (59.9%) and pain not related to overuse (44.4%). The least common complication was Injury caused by loss of sensation (2.2%). Among the 45 patients, the average depression score is 11.89 (11.89  $\pm$ 4.21). The WHODAS scale identified that majority of the respondents (75.6%, n=34) had some level of difficulties in participation. Maximum subjects (26.7%, n=12) had mild level of difficulties as compared to only 4.4% (n=02) had extreme level of difficulties in participation. Majority (77%, n=35) of the subjects did not experienced any clinical sign of depression. Only a few patients (4.4%, n=2) had possibility of major depression. Independent Sample t test find out significant association with wage earning status and WHODAS score.

**Conclusion:**

Study revealed that majority of the patients were suffering from secondary complications like bowel dysfunction, spasticity and pain not related to overuse which prevents them from performing their activities of daily living. It is also found that the less physical activity of patients and as well social work of SCI patients in the community. Physical activity was less than average. From this study it is found that majority of the patients had mild to moderate depression among the patients.

## 1.1 Introduction

Spinal cord injury is one of the most debilitating and devastating injuries in the world. It is a catastrophic and devastating condition that often affecting healthy and young individual. This debilitating condition not only creates enormous physical disability but also emotionally depress the patient. It causes important changes within an individual physical and psychological relationship with their environment.

After five years discharge from (CRP) Centre for the Rehabilitation of the Paralyzed, try to observe all one year patient. It is suspected that five years later what will be the condition for those patients who were discharge from specialized rehabilitation center. Spinal cord injuries are highly disabling and deadly injuries. In a spinal cord injury (SCI), the structures and functions of the spinal cord are damaged by trauma, inflammation, tumors or other causes, resulting in dysfunction of motor, sensory and autonomic nerves below the damaged level. Based on their etiology, SCIs can be divided into two different groups: traumatic spinal cord injuries (TSCI) and non-traumatic spinal cord injuries (NTSCI) (Yang, et al., 2014).

Life expectancy after SCI is markedly reduced due to secondary complication, severity of injury, social deprivation, and lack of proper rehabilitation. Evidence from Cripps (2011), showed that global prevalence of SCI was 236 and 1009 per million which was similar to a result found in 1995 by Blumer & Quine (about 110-1120 per million of population) (Fehlings, et al., 2014). Recently performed a comprehensive review of global epidemiology for SCI and noted prevalence rates ranging from 236 to 1009 per million. Data on incidence are predominantly from developed regions,

including North America (39 per million), Western Europe (16 per million), and Australia (15 per million)(Burns & O'Connell, 2012).

There are few publications available about life expectancy and the daily life of persons with SCI in low income countries. Those few publications identified and the study findings confirm that individuals with SCI are experiencing a high occurrence of pressure sores and urinary tract infections; it is leading to unnecessary suffering, often causing premature death. Pain and depression are frequently reported and stigma and negative attitudes are experienced in society. Lack of appropriate wheelchairs and services, limited knowledge about SCI amongst health care staff, limited access to health care and rehabilitation services, loss of employment and lack of financial resources worsen the daily challenges (Qderud, 2014).

A person with spinal cord injury is at immediate risk of respiratory and cardiac failure which may lead to death in the acute phase. Those who survive the acute phase, faces a lifelong risk of secondary complications such as pressure ulcers, urinary tract infections, deep venous thrombosis, contractures, chronic pain and spasms.

Trauma to the spinal cord may result from a road traffic accident (RTA), fall, assault and recreational or occupational accident (Anon, 2018). The World Health Organization informs that up to 90% of all spinal cord lesions are due to trauma and that the leading cause globally is RTA (Mock, 2008).Countries and regions where RTA is the leading cause of TSCI are mostly of high income and in African cities and towns where there is dense traffic of four, three and two-wheeled motorized vehicles. Worldwide, falls from high are the second leading cause of traumatic Spinal Cord Injury although in some parts of India, Nepal, South Asia, Estonia and Ireland it is reported the first leading Cause (Moshi, et al., 2017)



### **1.1.1 Background**

Spinal cord is a neural element in the spinal canal which can lead resolving or permanent neurological deficit (New & Marshall, 2013). It also affects a person's quality of life as well as a threat of national economy (Regan, et al., 2009). According to Norton (2010) statement, spinal cord injury can be define as the occurrence of an acute traumatic lesion of neural elements in the spinal canal (spinal cord and caudaequina), resulting in temporary or permanent sensory and/or motor deficit.

There are two type of SCI injury which was based on functional level and the extension of the injury like: paraplegia and tetraplegia. Paraplegia means the decrease or loss of motor and/or sensory function in the thoracic, lumbar or sacred segments of the spinal cord. The trunk, pelvic organs, and lower limbs are affected based on the level of injury. On the other hand tetraplegia refers decrease or loss of sensory and motor function in the cervical segments of the spine.

According to the extension of injury there are two type of SCI injury, like: complete and incomplete. When there is no preservation of sensory or motor function bellow the neurological level that is called complete injury. If there are some preservation of sensory and/or motor function bellow the neurological level is called incomplete SCI (White &Black, 2016).Incomplete injuries are injuries where partial preservation of sensory and/or motor functions is found below the neurological level and includes the lowest sacral segment (Hossain, et al., 2008) . SCI injury can be traumatic or non-traumatic.

The most common causes of traumatic injury are road accidents, falls, diving accidents, gunshot wounds etc. non traumatic injury mainly occurred by consequence

of pathology, such as vascular dysfunctions, degenerative joint disease, neurological diseases, neoplasia (Lee, et al., 2014).

Research shows that it is occurred by traumatic or non-traumatic etiologies. Traumatic spinal cord injury is caused by direct or indirect trauma. In developing countries, there are three main causes that patient is admitted into hospital. Those are fall from height, transportation accident and being struck by an object (Kennedy & Chessell, 2013). Trauma, compression, or total/partial rupture of nerve transmission are the main causes of rupture of spinal cord injury (Ferreira & Matao, 2017).

The non-traumatic cause is spinal tumor, Tuberculosis of spine, transverse myelitis, physical assault, physical weakness etc. (Chen, et al., 2013). The situation is quite different for developing country than developed country. The main causes of SCI in Bangladesh are fall from height, fall of object, RTA, bull attack, other traumatic, and non-traumatic (Rahman, et al., 2017).

Therefor in India, people are at a greater risk of having spinal injury due to fall from height or fall of a heavy object, RTA. They have some lack of safety precautions such as lack of fencing to the wells, roof, and staircase and have poorly built/substandard homes (mud homes) (Pandey, et al., 2007). Kong (2013) stated that, spinal cord may damage by producing inflammation, ischemia, and toxicity and it may lead to primary nerve injury.

SCI incidence rate is 15 to 40 per million throughout the world. SCI is a male dominant injury (Quadir, et al., 2017). Day by day the incidence rate of SCI is increasing According to WHO (2013 estimation, the incidence rate of SCI was 250,000–500,000 cases every year. According to Islam (2011) statement, physical damage is the vital health problem in Bangladesh which carries a high rate of

morbidity and mortality and SCI continues to be a major cause of disability throughout Asia as well as in Bangladesh.

The incidence rate of spinal cord injury is significantly higher in low income countries than higher economic countries (Hosssain, et al., 2016). Most data on survival after spinal cord injury in LMICs are obtained retrospectively from hospital records and focus on acute survival during the period of hospitalization immediately after spinal cord injury.

The few studies that have looked at survival after discharge in LMICs (Zimbabwe, Nepal, Sierra Leone and Bangladesh) report survival ranging from 30 to 75% between 1 and 5 years after discharge (Burns & O'Connell, 2012). In Pakistan, it was found that poor or appropriate knowledge was significantly associated with development of pressure ulcer where level of knowledge was based on the training and occupation of the participants. Meanwhile, attitude and practice were also significantly associated with the increased level of knowledge (Zeb, et al., 2015).

### **1.1.2 In Context of Developed Countries**

The incidence rates for traumatic spinal-cord injury in the USA range between 28 and 55 per million populations, with about 10,000 new cases reported every year (Blackham, et al., 2009). Published report shows that the incidence rate of SCI is higher in United State than the rest of the world and it is average 40 per million (DeVivo, 2012). According to Medola (2011) estimation in Brazil approximately 11,300 individuals become paraplegic or tetraplegia every year. The incident rate of SCI progressively increased as in Norway, the SCI incidence rate was increased from 6.2 per million to 26.3 per million populations in the last 50 years (DeVivo, 2012). It is estimated that global SCI new in 40 to 80 case per year, it is based on the quality country level, it is mean every year 250000 and 500000 people become SCI in the develop country. This incidence rates tend to be higher in North America than in Europe, possibly due to higher rates of violence in the USA.

Prevalence rate in Canada (traumatic and non-traumatic combined) of 2525 per million population, or 85 000 people, in 2010, in Finland it is 280 per million, in Australia 367, in china 60.6 and in the Tianjin it is 23.7 per million. Norwegian counties showed a steady increase in the incidence of traumatic Spinal Cord Injury by decade between 1952 and 2001, from 9.9 to 34.5 per million in men and from 1.9 to 8.2 per million in women (Lopez, et al.,2010).

In developed countries life expectancy has increased since the 1950s. High-income country showed a steady increase in life expectancy for people with SCI. A study in the USA observed a 40% decrease in mortality between 1973 and 2004 during the first 2 years post-injury. Following Secondary conditions of SCI are no longer the main cause of death of people with SCI in high-income countries (Amarin&Obeidat, 2010).

### **1.1.3 In Developing Country:**

Spinal Cord Injury is three to four times' high-income countries (Wyndaele&Wyndaele, 2006). Most people with SCI in a country such as Sierra Leone die within a few years of injury. In low-income countries, and in many middle-income ones, the availability of quality assistive devices such as wheelchairs is very limited, medical and rehabilitation services are minimal, and opportunities to participate in all areas of personal and social life are inhibited (Allotey, et al., 2003). People it is quite possible to achieve national development. But it is real phenomenon of our society that disable people are very often deprived of their social opportunity and their rights.

Similarly, there are few accurate data about survival following SCI in these countries (Qderud, 2014). However, our own estimates from one specialized service in Bangladesh indicate that 19% of people with SCI, who are wheelchair-dependent and survive until discharge, die within two years (Hossain, et al., 2015).

Persons with thoracic and lumbar injuries in developing countries have poorer first year survival than those with similar injuries in developed countries, persons with cervical SCI are even less likely to survive the initial injury and/or hospitalization in developing and resource poor regions, In the study from Sierra Leone, one of Africa's poorest countries, 17 of 24 individuals survived to hospital discharge, after which an additional 8 persons died in the community (Burns & O'Connell, 2012)

Most are young males dying from complications such as sepsis due to pressure ulcers (Hossain, et al., 2015). There is therefore a pressing need to find sustainable ways of supporting people with SCI in the community following discharge, particularly those at high risk of complications. Many patient die within a few years of discharge. The most common cause of death is septicemia caused by pressure ulcers (PU) or urinary

tract infections (Hossain, et al., 2016). Another leading cause of death early after injury was pulmonary embolism (De Vivo, et al., 1989).

Mortality rates from injuries are higher for people from poorer economic backgrounds than those with higher incomes and health care professionals and organizations dealing with people with disabilities experience that individuals with spinal cord injury (SCI) in low income countries face serious challenges in their daily lives (Rathore, et al., 2012).

#### **1.1.4 In Context of Bangladesh**

Bangladesh is developing country and most densely populated country in the world. Approximately hundred and fifty million people live in this small country. Near about 10% of total population are disable in Bangladesh where 43% are physically disable (JICA, 2002).

The situation of the Bangladesh in the access to support service area has very little. It is not people who sustain a SCI are discharged home with very little access to support services. It is not surprisingly happened that they frequently develop life threatening complications. There are no accurate data on the incidence of spinal cord injuries (SCI) in low-income countries such as Bangladesh but most working in the area believe that it could be as high as 70 per million. (New & Marshall, 2013) (Elshahidi, et al., 2018)

Disable population and also aging population is increasing with the growth rate of all population. There is no structured health-care delivery system for spinal injuries in Bangladesh. Bangladesh has not had any registry or proper demography study so far. People having spinal injury can go to any hospital of their choice for management, SCI is more prone to rural area rather than in urban area about 61.1% of the respondent was from rural area (Rahman, et al., 2018).

In the context of low-income and middle-income countries people with SCI are susceptible to life threatening complications after discharged from the hospital. A study conducted in Bangladesh showed that 19% of the wheel chair dependent patients discharged from a large SCI unit in Bangladesh die within 2 years of discharge due to pressure ulcer (Hossain, et al., 2018).

These studies are either very small to follow-up so it will not provide precise and difficult estimates of survival. In this research only 50 patients follow up by simple random sampling, the sample only included those in whom the hospital kept medical records on following discharge. This inclusion criterion is bit problematic because it is not known that how many patients was discharge in the admission time.

Few patient were readmitted form long ago, were included from the 1980s and 1990s, suggesting that the medical records did not document all patients discharged from the hospital. It is one of limitations of existing data on survival after spinal cord injury in low middle income country. Researcher conducted a cohort study to determine survival after spinal cord injury in Bangladesh. Particular care was taken to clearly define the study cohort and achieve as complete a follow-up as is possible in a low middle income country.

Research followed up patients 5 years after they had been discharged, as because it is long enough time for the understanding survival rates and the secondary complication. But it is not so long time to chance large loses in the follow up.



## **1.2 Justification of the Study**

Spinal cord injury (SCI) is a devastating condition which can affect a person's physical, mental, familial as well as social life (Rahman, et al., 2017). It is a life altering experience (Merghati-Khoei, et al., 2017). This catastrophic event affects individual health. It is not only responsible to create physical disability but also emotionally depress the patient (Wu, et al., 2012).

SCI is the important health problem in this subcontinent and it carries high rates of morbidity and mortality (Agarwal, et al., 2007). It was found that only 16.4% of the study population survived for 10 years, which was much lower than figures for various developed countries where a 10 year survival rate was observed in around 80% of affected persons in France.

The higher number of deaths of persons with SCI at home in the present study may indicate the negative social acceptance of such people, lack of proper reintegration in society (Razzak, et al., 2011). More than 90% of deaths that result from injury occur in low and middle income countries, and mortality rates from injuries are higher for people from poorer economic backgrounds than those with a higher income (WHO, 2010). Poorer people have an increased risk of injuries, and they are hardest hit by the financial pressure resulting from injuries (WHO, 2010). The global incidence of SCI every year ranges between 5.3 and 57.8 per million people, whereas the individuals between 20 and 40 years age are highest incidence of SCI.

The largest study of survival in people with spinal cord injury after discharge from hospital in a LMIC was a retrospective chart audit conducted in India. That study reported survival of 86% 5 years after discharge in a sample of 537 patients discharged from a tertiary rehabilitation facility between 1981 and 2011 (Barman, et al., 2014). Septicemia as a result of urinary tract infections and pressure sores was

still the leading cause of death and had the greatest impact on life expectancy and daily life amongst individuals with SCI.

The findings confirm that individuals with SCI and their families in low income settings are facing major challenges in their daily life, because of limited financial, medical, social and technical support (Pandey, et al., 2007). Poverty has an even greater impact on people with SCI in low income countries, because of the daily challenges presented by the low standard of living. Poverty itself is contributing to individual suffering and a high mortality rate by limiting access to rehabilitation services including appropriate wheelchairs and medical treatment for complications like infections, pressure sores and respiratory problems, common to people with SCI (Qderud, 2014).

The management of SCI is undergoing a renaissance. Now a day's conservative, non-interventional approaches are being questioned, and a more aggressive evidence-based approach is evolving. It is our aim to find out and understand the pathophysiology, complication and behind the reason of mortality rate of SCI patients. After completion of this follow-up we are able to understand behind the reason of mortality, the reason of secondary complication, the current situation of employment that will shed on further light to steps being taken for prevention of mortality and secondary complication. By this study we can make further plane about community reintegration and what would the better intervention for this particular population or can think about community base rehabilitation.

### **1.3 Research Question**

What are the secondary complications developed and mortality rate among spinal cord injury after 5 years duration?

#### **1.4 Operational Definition**

**Spinal Cord Injury:** A spinal cord injury (SCI) is damage to the spinal cord that causes changes in its function, either temporary or permanent. These changes translate into loss of muscle function, sensation, or autonomic function in parts of the body served by the spinal cord below the level of the lesion.

**Secondary Complication:** Spinal cord injury (SCI) is a serious medical condition that causes functional, psychological and socioeconomic disorder. Therefore, patients with SCI experience significant impairments in various aspects of their life. Acute and long-term secondary medical complications are common in patients with SCI.

**Premature Death:** Premature deaths are deaths that occur before a person reaches an expected age (e.g. age 75). Many of these deaths are considered to be preventable

## **1.5 Outline of Thesis**

The rest of the thesis is outlined as follows. **Chapter 2** will review the current and past literature, mortality, secondary complication, Quality of life, Depression after Spinal Cord Injury. The review includes theories related to SCI and their impacts in the life of individual and the family in context of developed countries, developing countries and Bangladesh. This chapter also reviews the literature on prevalence and incidence of PU among SCI in Bangladesh and other countries. **Chapter 3** will provide an overview of different sets of procedures used in this study, sampling procedures. **Chapter 4** will report the findings of the result. **Chapter 5** will provide the Discussion. **Chapter 6** will provide an overall conclusion, recommendations, strengths and limitations of the study. In addition, this chapter also includes suggestions for future research.

## 2.1 Introduction

Spinal cord injury (SCI) is a serious medical condition that results; it is make effect on the functional, psychological and socioeconomic disorder. As a result patients with SCI suffering different significant impairments in various aspects of their life.

We do rehabilitation in the rehabilitation area and other treatment approached such as surgical, therefore to improve their functional level, decrease secondary morbidity and enhance health-related quality of life and facility them in the community with their spontaneous participation in own environment (Sezer, 2015).

Acute and long-term secondary medical complications are common in patients with SCI. Chronic complications especially further negatively impact on patients' functional independence and quality of life. Therefore, prevention, early diagnosis and treatment of chronic secondary complications in patients with SCI are critical for limiting these complications, improving survival, community participation and health-related quality of life.

Internationally incidence rate for SCI range from 10.4 to 83 case per million of population, with significant difference between different country or region (Ning, et al., 2011). In Bangladesh, it was found that 79.75% were paraplegic rather than tetraplegia 20.25% which is different from findings in other country studies whereas in Pakistan it showed that 47.2% were tetraplegia and 52.8% paraplegic. The worldwide incidence of SCI is 10.4 and 83 per million per year and the mean age is 33 years old, male and female ratio is 3.8:1 and one- third of the patients are tetraplegia all over the world (Wyndaele & Wyndaele, 2006). Moreover, 2.5million people live with SCI around the world (Oyinbo, 2011). In Asia the incidence rates of SCI is ranged from

12.06 to 61.6 per million and the average age is 26.8 to 56.6 years old, men are more vulnerable than women also in traumatic spinal cord injury main causes are motor vehicle collisions (MVCs) and falls (Ning, et al., 2012).

The retrospective study of Japan showed that the annual incidence of spinal column injuries ranges from 19-88/100,000. 15-50 per million per year is the incidence of spinal cord injury. 480-813 per million is the prevalence of SCI. In Pakistan exact incidence of these injuries in this region is not known though there are few reports on demographics of spinal injuries (Qureshi, et al., 2010).

The primary causes of death were pneumonia, accidents and suicides. Septicemia, pneumonia and pulmonary emboli are the highest ratios of actual to expected deaths where pneumonia was the leading cause of death. The secondary causes of death were accidents and suicides. Both accidents and suicides were the leading cause of death. Actual-to-expected deaths Septicemia had the main ratio.

The principal causes of death among paraplegics' accidents, suicides and cancer were major where pneumonia was the leading cause of death among quadriplegics. Until the mid-1970s overall leading cause(s) of death were traditionally known renal failure and other urinary tract complications, which decline in their role in recent data, reflect a significant as the primary killer of SCI patients (Rose, 2012). It was a general agreement in many previous literatures for the person with spinal cord injury patient said that life expectancy is remains below normal compare with normal medical management. It is change after Second World War. The mortality rate is change day by day. Before Second World War it was reported 60- 80%. But now it is going to change as because develop the SCI treatment procedure, well rehabilitation program include and included regular follow up program and also telephone base intervention.

The mortality rate is decreasing to 30% in 1960, 15% in the 1970s and down to 6% in the 1980s (Hartkopp, et al., 1997). Respiratory problem is most common associated with SCI patient for the cause of morbidity and mortality at any stage in chronic or acute. It is depends on the level of injury (Sezer, 2015). Recently studies suggested respiratory cause is the most common, and pneumonia and also urinary tract infection. On the other hand, septicemia cardiovascular disease and also suicides is the other major cause (Hartkopp, et al., 1997).

Many die within a few years of discharge. The most common cause of death is septicemia caused by pressure ulcers (PU) or urinary tract infections (Hossain, et al., 2016). Another leading cause of death early after injury was pulmonary embolism (De Vivo,et al., 1989). According to Stojadinovic(2013) patients with cervical and high thoracic SCI are at higher risk for developing atelectasis and pneumonia due to paralysis of the respiratory muscles below the level of injury, resulting in a weak cough mechanism and difficulty mobilizing lung secretions (Sezer, 2015).

PU defined as breaks in the integument caused by continuous pressure of the body weight to skin have been implicated as one of the most frequent causes of death in elderly, wheelchair and bed-bound individuals. As many chronic wound types, PU is multifactorial disease. Multiple physical factors lead to the development of PU including: static pressure or stress, shearing forces, friction, and moisture, but these alone are insufficient to produce tissue damage resulting in a PU occur most commonly on the lower half of the body, particularly over the sacrum (43%), greater trochanter (12%), heel (10%), ischialtuberosities (5%), and lateral malleolus (6%).It is estimated that PU are responsible for approximately 8% of deaths in people with SCI in high-income countries (Makhsous,et al., 2009).This figure is probably much higher in low-income and middle-income countries (Arora, et al., 2015).



Autonomic dysreflexia(AD) is a well-known medical emergency. It generally occurs in patients with SCI at levels of T6 and above. AD is characteristic for the chronic stage but may appear any time after SCI. It is reported that the life time frequency among patients with SCI is 19%-70% (Sezer, 2015). It is more common in patients with cervical and complete lesions.

AD is caused by spinal reflex mechanisms initiated by a noxious stimulus entering the spinal cord below the level of injury. This afferent stimulus generates a sympathetic over activity leading to vasoconstriction below the neurological lesion, along with involvement of splanchnic circulation that causes vasoconstriction and hypertension (Krause, et al., 2008). The excessive parasympathetic activity (and lack of sympathetic tone) leads to vasodilation above the level of the lesion and is thought to be responsible for headache, flushing, sweating and nasal congestion. The reflex bradycardia is secondary to vagal stimulation. Bladder distension is the most common triggering factor for AD. The distension can result from urinary retention or catheter blockage and accounts for up to 85% of cases. The second most common triggering for AD is bowel distension due to fecal impaction (Soden, et al., 2000).

Spasticity is a common secondary impairment after SCI characterized by hypertonus, increased intermittent or sustained involuntary somatic reflexes (hyperreflexia), clonus and painful muscle spasms. Spasticity affects 70% of patients with SCI and causes considerable disability for many (Sezer, et al., 2015). Symptoms of spasticity are experienced by the majority of individuals with SCI and are a possible contributor to reduced Quality of Life (QOL). Unequivocally, ‘spasticity’ is understood to be among the symptoms resulting from injury to the upper motor neurons within the central nervous system (CNS) and is a common but not an inevitable sequel of spinal cord injury (SCI) (Adams, et al., 2005).

Bladder management is also important for the SCI patient. Intermittent catheterization also helps to decrease the urinary tract infection for the person with SCI. Intermittent aseptic catheterization in acute phase and self-catheterizations in chronic stage decrease the complication of infection in the urinary tract, hydronephrosis and renal failure. Literature suggested that circulatory disease caused by arteriosclerosis and diabetes mellitus have been increase among paraplegics (DP, et al., 1999).

Through the recent work of a number of North American and British researchers, a clearer picture is now emerging of the survival experience of people who have sustained a traumatic spinal cord injury.

Studies of long-term survival show considerable agreement about the life expectancy of someone with a spinal cord injury and the factors affecting survival. In 1961, Breithaupt and colleagues published the accounts of long-term survival of traumatic paraplegics, and found that on average, individuals could expect to live to 55 or 60 years of age, depending on their age at the time of injury (Foote, 2003).

Depression is common among traumatic paraplegia or tetraplegia (Howell, et al., 1981) following their sudden one of the most devastating of all non-fatal injuries (Whalley, 1992). The prevalence of depression after SCI is high and it is well-established (Kalpakjian, et al., 2009).

Chronic pain is one of the frequent secondary complications for individuals with SCI, with up to 80% of patients with SCI reported to suffer from it. Chronic pain may lead to functional disability and emotional discomfort and may impact negatively on community participation and quality of life (Nielsen, 2003). After SCI, chronic musculoskeletal pain, a type of nociceptive pain, may occur with abnormal posture,

gait and overuse of structures such as the arm and shoulder. Neuropathic pain can occur above the level, at the level or below the level of injury. Above the level neuropathic pain may arise from complex regional pain syndromes and compressive mono neuropathies (Sezer, 2015).

Researcher conducted this study in order to compare the survival rates and the mortality of long-term SCI persons versus general population, and to clarify the risks of complicated diseases on SCI. Each year, approximately 10 000 persons in the United States incur a spinal cord injury (SCI) requiring hospitalization. The costs of these injuries to both individuals and society are staggering.

Moreover, with advancing medical technology and increasing life expectancies, the costs of SCI are increasing at a rapid pace. Given a current political climate that demands cost containment and health care reform, it is essential to have rigorous estimates of the aggregate costs of SCI to society to ensure that adequate funds are allocated to prevention activities, appropriate research initiatives aimed at improving the quality of life for persons with SCI, and the medical management of these individuals for whom the government often serves as the responsible third-party payer.

Therefore, the purpose of that study was to estimate the national aggregate direct costs of SCI in the United States from a public health perspective focused on the leading causes of these catastrophic injuries (DeVivo, 1997).

Life expectancy after spinal cord injury having carried out a cumulative survival analysis in patients admitted to a specialized Spinal Unit over a 40 year period. Results showed that the projected mean life expectancy of SCI people compared to that of the whole population approached 70% of normal for the individual with

complete tetraplegia and 86% of normal for complete paraplegia (Frankel, 2007). Patients with an incomplete lesion and motor functional capabilities (Frankel Grade D, 2009) were projected to have a life expectancy of at least 92% of the normal population. In examining specific causes of death, the current study is complementary to the former study as it seeks to provide explanations for the observed reductions in life expectancy for different groups of SCI individuals (Soden, 2000).

Prevention is better than cure lost spinal cord function following spinal cord injury there was still a very long way to go to restore. Spinal trauma which could have been prevented, this is the result of spinal cord injuries.

The Japanese Medical Society of Paraplegia (JMSOP) which is the prevention Committee conducted the first nationwide epidemiological survey in Japan in order to obtain basic data to organize a prevention campaign for SCI and spinal injuries (Shingu, et al., 1994). In rehabilitation program reconstructive procedures are effective. Prevent weight bearing otherwise wound or pressure ulcer may increase (Srivastava, et al., 2009). The proper wound management immediately after the injury, health education programs to create awareness among the public and establishing an ICU facility in the hospital would definitely decrease the morbidity and the mortality (Marulappa, et al., 2012).

Trauma care requires to be singled out by the availability of rehabilitative care, prosthetic devices, and age appropriate and culturally sensitive because of significant problems world-wide. The most important medical need identified is the continuing lack of rehabilitation services for adolescents and youth with disabilities. Who have to rehabilitation any sort of care only 5 per cent receives in the United Nations

estimates that of those worldwide. Often in urban areas rehabilitative services tend to be intense and are very expensive. Often unavailable programs that require long-term residency are also to girls in societies where females are not permitted to travel or live on their own. Growing young person would need frequent replacements where prosthetic devices are often difficult and expensive to acquire.

Appropriate physical and psychological support developmentally services are often unavailable. At the side of infants and pre-school children unlike their non-disabled peers, adolescents and youth who receive medical care are often served in clinics (Groce, 1999).

Some of the changes involve the loss of motor function, inability to control bladder & bowel function and the vitiated sexual functioning. It also has an Impact on quality of life, life expectancy and economic burden (Ning, et al., 2010). The disease and injury which affect the spinal cord and damage the neurological level are the important health problem in our country; they carry high rates of morbidity and mortality (Hoque, et al., 1999).

In respect to these changes they are likely to have profound effect of an individual social and interpersonal relationship within their community (Foote, 2003). It is one of the most serious injuries that a person can survive. It is probably the most devastating of all the illness that can befall man. There are no effective restorative therapies for SCI as yet, so prevention is the best medicine at present.

Prevention is better than cure lost spinal cord function following spinal cord injury there was still a very long way to go to restore. Health management of persons with spinal cord injury (SCI) improved dramatically in the last several decades. In the past, representative complications of the spinal cord injury were decubitus and

urinary tract infection, and death by renal failure was the primary cause of death in paraplegics. Long-term disability or death is the cause of Spinal cord injury (SCI).

Leading to permanent paralysis by modern man, it is one of the most catastrophic lesions. The Spinal cord injury patients, the victims who are usually young and in their most productive stage of life multiple medical, social and vocational complications affect to them.

### **2.1.1 In Context of Developed Countries**

The incidence rates for traumatic spinal-cord injury in the USA range between 28 and 55 per million populations, with about 10,000 new cases reported every year (Blackham, et al., 2009). Published report shows that the incidence rate of SCI is higher in United State than the rest of the world and it is average 40 per million (DeVivo, 2012). According to Medola (2011) estimation in Brazil approximately 11,300 individuals become paraplegic or tetraplegic every year.

The incident rate of SCI progressively increased as in Norway, the SCI incidence rate was increased from 6.2 per million to 26.3 per million populations in the last 50 years (DeVivo, 2012). This difference is due to the fact that men are mostly exposed to the work or activities that make them vulnerable to SCI, while women generally do not go out for work and remain indoors.

Men are mostly exposed to the work or activities that make them vulnerable to SCI, while women generally do not go out to work and remain indoors (Razzak, et al., 2011). Simultaneously, in France, 52% were found to be tetraplegic, and 48% paraplegic. In England and Wales, more than half of all deaths (58.3%) occurred in hospital (Razzak, et al., 2011). In Australia, male is more affected than female in non-traumatic SCI and the ratio is 197:169 and the prevalence of paraplegia is more about 269 per million than tetraplegia (98 per million) (New, et al., 2013). Nwankwo&Uche (2013), found that in SCI, 31–45 years age group is the most frequently affected and male is more affected than female (4.3:1), 53% injury occurred in cervical spine, 22% thoracic spine and 25% lumbar spine injury. In United States the annual incidence of traumatic SCI is 40 cases per million or 1200 new cases each year (Rabadi, et al., 2013). The prevalence of SCI at 650–900 per million American epidemiological data approximately showed that (Genis, et al.,

2005). Expected data showed that the rates of adolescents with disabilities range from 108 per 100,000 in Myanmar to 6,726 per 100,000 in Canada (Groce, 1999).

In Japan from January 1990 to December 1992 a survey of traumatic spinal cord injuries was carried out by a statistical method of the nationwide epidemiological study showed that the incidence was 40.2 per million in the annual report of spinal cord injury. More caudal SCI was 3:1 is the ratio of cervical cord injuries (Shingu, et al., 1995).

The prevalence of SCI at 650–900 per million American epidemiological data approximately showed that (Genis, et al., 2005). Expected data showed that the rates of adolescents with disabilities range from 108 per 100,000 in Myanmar to 6,726 per 100,000 in Canada (Groce, 1999). In Australia a study showed that most devastating medical conditions are Spinal cord injury (SCI) or damage. In all facets of human functioning and existence it causes life changing consequences.

The incidence of Traumatic SCI a recent review reported that worldwide varied between 10-4 and 83 per million per year. About 15–17 cases per million per year over the past decade the age-adjusted incidence rate of TSCI in adults aged 15 years has remained at and older surviving to reach hospital. In currently 11.9 cases per million adults per year is the incidence in Victoria in Australia (New & Sundararajan, 2008).



### **2.1.2 In Context of Developing Countries**

There are lots of study was done about the effects of SCI. After SCI people have to suffer some complications like: neurological deficits, secondary health complications, psycho-social adjustment, lack of social and vocational opportunities, and environmental barriers. Those types of complications have a negative impact on community integration (Access Economics, 2009). SCI is not a generally progressive disease but it changes the entire life style ((Ferreira & Matao, 2017).

SCI not only affects individuals but also their spouses, parents, siblings and children and the significant cause of mortality and morbidity (Ali & Tawfiq, 2013). The life altering experience that affects not only the patients with SCI but also their Spinal cord injury results in a high level of individual disability, which is reflected in radical changes in lifestyle (Kawanishi & Greguol, 2013).

There are different type of complications may arise after SCI. SCI may lead to changes in motor, sensory and autonomic function. The other changes also involve with SCI, like inability to control bladder & bowel function, the vitiated sexual functioning and having high risk of developing of various complications including pressure sore. They usually losses their functional mobility and their psychological wellbeing also hampered (Van & Kayes, 2014).

A lesion of the spinal cord, results in paralysis of certain areas of the body, along with the corresponding loss of sensation (Peterson, et al., 2009). Paralysis of limb and other complication such as compression, contusion or laceration, disrupts autonomic function occurs at the site of injury or below the injury level commonly seen after SCI. Pain is one of the most common secondary complication comes after injury (Mothe & Tator, 2013). Various studies suggested that patients with spinal cord injury

suffer from depression, anxiety and their quality of life is remarkably lower compare to normal population (Van & Kayes, 2014).

Emotional and behavioral problems may develop or worsen after a SCI. There is often a period of adjustment after a spinal cord injury. Sometimes feelings of sadness or anxiety may develop due to SCI (Kalpakjian, et al., 2009). Spinal cord injury or damage can cause a wide range of impairments, activity limitations and participation restrictions, which has an adverse impact on the society (New, et al., 2013) Rahman (2012) stated that, daily activities are affected by deficit of motor function of SCI patients.

### **2.1.3 In Context of Bangladesh**

Bangladesh has very limited resources in this field. An epidemiological study was published by Hoque (1999). Another article was published in Bangladesh by Hoque(2012). Another two study was conducted by Rahman (2017), Razzak (2017) about epidemiology of SCI in Bangladesh.

Spinal cord injury causes burden and suffering not only of the victim but also to their families, to the health care system and to the community (Maharaj, 1996). Pressure ulcers are an important and potentially life threatening secondary complication of SCI. They can lead to further functional disability and fatal infections and surgical interventions can be required (Sezer, et al. 2015). The study done by C Joseph and L Nilsson Wikmar in 2015 shows that pressure sore is the dominant secondary health complication following SCI.

In developing countries like Bangladesh, the prevalence of pressure sore among SCI patient is very high (67.5% had pressure ulcer in study done by Quadir(2017). A study was done by Hossian(2016), in Bangladesh, shows 2 years of survival rate in SCI patients after discharge from Rehabilitation center and the main cause being sepsis due to pressure ulcer (56%). Pressure ulcers account for one-fourth of the cost of caring for SCI patients. Prevention of these ulcers would cost less than one-tenth the amount spent on treatment (Byrne, et al. 1996). So, the prevention should be emphasized more.

This chapter will describe the overall procedures for conducting this study. **Section 3.1** explains the objectives of this study. **Section 3.2** will give a brief explanation on study design and study population, while **section 3.3** will provide a brief explanation on study area and study period. **Section 3.4** will define the sample size and sampling technique. **Section 3.5** will explain the inclusion and exclusion criteria of this study. Data collection tools and data management and analysis will be explained in **section 3.6** and **section 3.7**, respectively. **Section 3.8** will provide the quality control and quality assurance information. **Section 3.9** will describe the process of ethical consideration used in this thesis.

### **3.1 Study Objectives:**

#### **3.1.1 General Objective**

- To determine current status of person with SCI who had discharged from hospital five years ago.

#### **3.1.2 Specific Objectives:**

- To explore socio-economic status of spinal cord injury patient.
- To find out secondary complication and mortality rate.
- To find out psychological status and quality of life.

### **3.2 Study Design and Study Population**

That was a cohort retrospective observational study of the spinal cord injury patients admitted for rehabilitation at Centre for Rehabilitation of Paralyzed (CRP) in Bangladesh. Records of all admitted patients with spinal injuries from January 2011 to December 2011 were following up by phone call and when it was needed then data was collected by patient's home visit. In every phone call to the patient researcher were fill up preform pretested scale of SCI secondary condition, WHODAS scale, SF-12 scale, CESDE-R scale and researcher was also asked patient about his activities.

Study population was taken from spinal cord lesion unit (SCL) at center for the rehabilitation of the paralyzed (CRP) in Bangladesh. Admitted spinal cord injury patient who was completed total rehabilitation and discharge from January 2011 to December 2011 at CRP.

### **3.3 Study Area and Study Period**

The study was conducted at Centre for the Rehabilitation of the Paralyzed (CRP) in Bangladesh. It is 115 -bed rehabilitation center for SCI patients including other neurological departments located in Savar, the capital city of Bangladesh. It is one of the biggest rehabilitation centers for spinal cord injury patients in Bangladesh. The study was conducted in the SCI department after the approval from the Ethical Review Board (ERB) and permission from the head of the respected department. The duration of study was six months.

### **3.4 Sample Size and Sampling Technique**

The study conducted at CRP by Hossain (2016) shows that the CRP admits approximately 390 patients a year with recent spinal cord injury. This makes the CRP one of the largest acute spinal cord injury units in Bangladesh. It receives referrals from all over Bangladesh including referrals from other hospitals. Therefore, total 295 populations were considered for this study. In Bangladesh there is no article to determine the prevalence of Spinal cord injury patient. Sample size was estimated according to following formula with 95% confidence level, 5% margin of error and a total population of 295 patients, from that sample size was 168. I collect 50 patients from that by using simple random sampling in the Microsoft Excel Worksheet.

The data was collected from December 2017 to April 2018. Therefore, all the patients with recent spinal cord injury admitted to CRP during this period were included in this study based on the inclusion and exclusion criteria. The total collected data was 50. Meanwhile, that was an academic research and had time limitations. So that, it was not possible to collect data from total sample size.

A simple random sampling had been used for this study. Researcher acknowledges that this type of sampling method occupies low cost and researcher has a no freedom to choose whomever they find. Researcher selected this technique as it is easiest, researcher will not bias to collect the data, so every patient have equal chance to participate.

### **3.5 Inclusion and Exclusion Criteria**

#### **Inclusion Criteria**

- All spinal cord injury patients who were discharge in 2011 from CRP.

#### **Exclusion Criteria**

- Patient who were not diagnosed as a spinal cord injury in 2011 at CRP.
- Patient who already died.

### **3.6 Data Collection Tools**

All preformed pretested questionnaire was used for this research and it was also translated in Bangla. By this questionnaire, socio-demographic and social and family related variables such as age, sex, religion, living area, neurological level, ASIA, SCIM score, marital status, educational level, monthly income, number of children, duration of marital life this type of information was taken.



**3.7.1:** Socio-demographic questionnaire,

**3.7.2:** The burden of complications was measured using the SCI Secondary Conditions Scale (SCI-SCS).

**3.7.3:** Depression was assessed using the Center for Epidemiologic Studies Depression Scale revised version (CESD-R).

**3.7.4:** Health-Related Quality of Life was self-assessed using the Short Form Health Survey-12 (SF12) questionnaire.

**3.7.5:** Independence was assessed using the Spinal Cord Independence Measure Self Report (SCIM-SR). The details of each section were explained as follows:

**3.7.1: Socio-Demographic Questionnaire**

This questionnaire consisted of 12 items to assess the respondents' socio-demographic data including age, gender, educational status, marital status, occupational status, residence status, living area, number of caregivers and relationship between caregiver and use wheel chair or not.

**3.7.2: The Burden of Complications was Measured Using the SCI Secondary Conditions Scale (SCI-SCS).**

This is a 16-item scale. Each item is scored from 0 (did not experience the complication in the last 3 months) to 3 (significant or chronic problem over last 3 months). The score for each item was determined by the assessor after asking the participant any question deemed relevant and after physically examining the participant if necessary. The scores was summed to provide an overall score with a total possible score of 48, where 0 represents no complications and 48 represents severe complications over the last 3 months. Incidence of complications over the two

year period after discharge was not measured because doing so would require ongoing monitoring of participants in the Control group, which was not feasible and could contaminate the intervention.

**3.7.3: Depression was Assessed Using the Center for Epidemiologic Studies Depression Scale Revised Version (CESD-R).** The CESD-R is a widely used instrument to screen for depression and depressive disorders. It measures symptoms defined by the American Psychiatric Association Diagnostic and Statistical Manual (DSM-IV) for a major depressive episode. The questionnaire contains 20 items each scored on a 4-point scale. Each item refers to feelings in the past week. Scores are tallied to a total score of 60 where higher scores are indicative of more depressive symptoms. The CESD-R has been translated into Bangla. The questionnaire was administered as a self-reported questionnaire under the guidance of the assessor.

**3.7.4: Health-Related Quality of Life was Self-assessed Using the Short Form Health Survey-12 (SF12) Questionnaire.** The SF12 consists of 12 questions designed to measure functional health and well-being from the individual's perspective and is derived from the physical and mental domains of the SF36. The questionnaire had been translated into Bangla and was administered as a self-reported questionnaire under the guidance of the assessor.

### **3.8 Data Management and Analysis**

The quantitative and descriptive analysis was carried by using MS EXCEL and SPSS 16 version. Where there was frequency table of the variables with mean and standard deviation, cross tabulation along with association among the socio demographic

variables with other factors by using statistical test such as chi square test was also tried to carry out. Subjects were grouped according to marital status (single, married or other).

### **3.9 Quality Control and Quality Assurance**

The questionnaire had been carefully designed and English-Bengali version was used for data collection to maintain the quality of the data. Before actual data collection time, the questionnaire (tool) was checked for clarity, comprehensiveness, and content validity by an expert. Data were collected carefully and confidentiality of recipient information was maintained during whole period of research. Researcher accepted the answers of participant whether they are right or wrong without researcher influence. The researcher checked all data several times to maintain accuracy. The collected data were then reviewed and checked for completeness and consistency by the principal investigator on a regular basis.

### **3.10 Ethical Consideration**

Approval from ethical review board of Bangladesh Health Professions Institute (BHPI) and hospital administration was obtained from intended hospital (CRP) as well as department, patients and caregivers. The researcher had been collect data through face to face interviews and as well through the telephone. In case of face to face interviews, written consent was taken from the participants and caregiver before collect the data. Verbal consent was taken from participants and care giver for telephone interview.

The patients and caregivers were informed of the purpose of the study that they had the right to refuse and to participate. Furthermore, the patients and caregivers were informed that they can refrain from answering any questions and they can terminate at any time. Confidentiality of the patients and caregivers were maintained all times.

In this chapter the results of this study is presented under the following headings:

1. Respondents' socio-demographic characteristics.
2. Distribution of secondary complications followed by SCI.
3. WHODAS – v2 – Participation Items.
4. Distribution of domains of Quality of Life.
5. Association of secondary complications with socio-demographic characteristics of SCI patients.

The participants in this study involved paraplegic and tetraplegic patients with spinal cord injury at Centre for the Rehabilitation of the Paralysed (CRP). It is the biggest rehabilitation center in Bangladesh. Three hundred and fifty participants admitted to CRP in 2011 with a recent SCI survived until discharge. Among them, 55 died following discharge before being interviewed. Another participant was excluded because a head injury prevented him from speaking. Thus, 295 potentially eligible, 50 patients were selected randomly were located and interviewed.

#### **4.1 Respondents' Socio-demographic Characteristics**

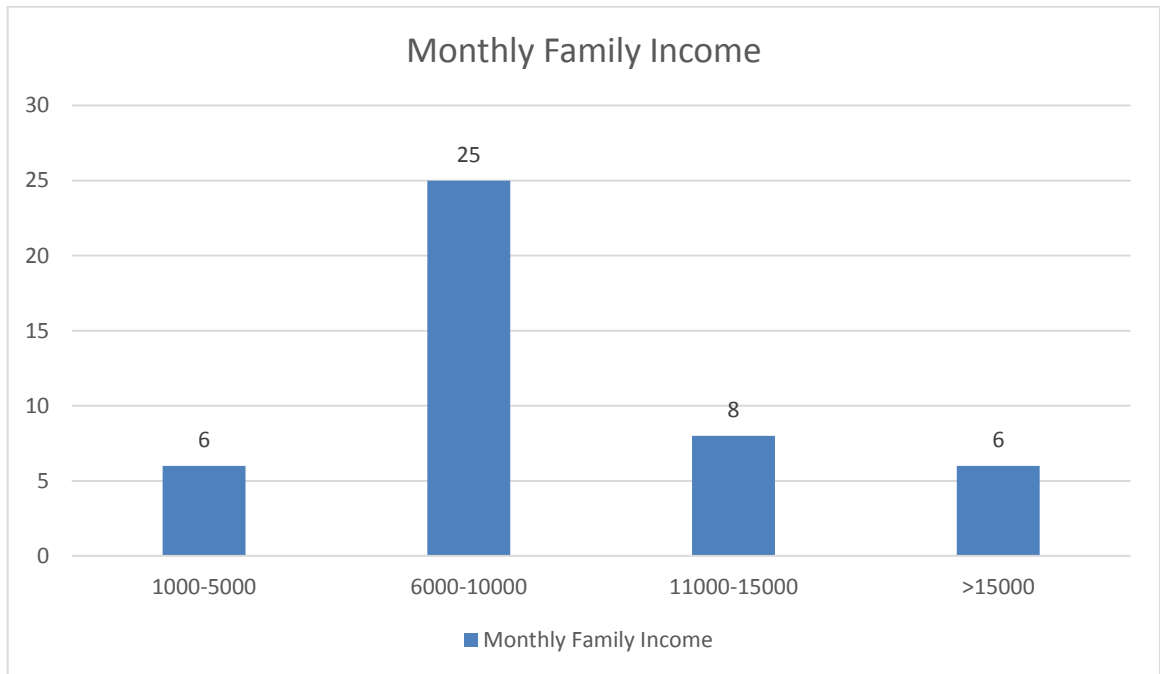
The socioeconomic status out of 50 SCI patient studied in this study, Majority of them were male (88%, n=44) where female 12%, n=6) married (70%, n=35), unmarried (26%, n=13) widowed or separeted (4%, n=2)and living in own house (90%, n=45). Wife/husband (74%, n=37) was found as most common type of primary caregiver followed by mother/ father (14%, n=7). More than half of the subjects stated that they are neither wage earner of his/her family (68%, n=34) nor currently employed in any occupation (56%, n=28). Among the subjects who were

employed 16% were small business owner, 14% were shopkeeper and 8% were farmer (Table-4.1.1).

**Table:4.1.1 Distribute Sciodemographic Data**

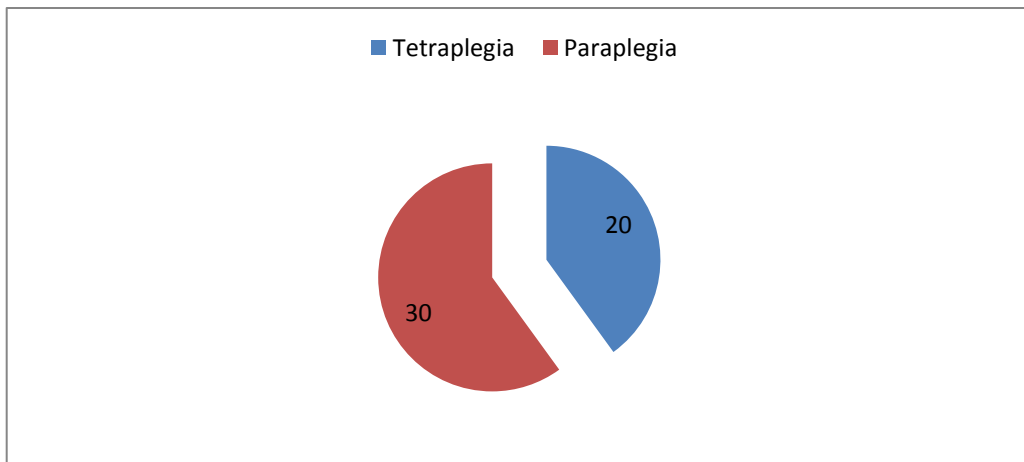
<b>Varibale Name</b>	<b>n (%)</b>	<b>Varibale</b>	<b>n (%)</b>
<b>Sex</b>		<b>Marital status</b>	<b>35 (70)</b>
<b>Male</b>	44 (88)	Married	13 (26)
<b>Female</b>	6 (12)	Unmarried	2 (4)
<b>Accomodation</b>		<b>Primary Caregiver</b>	<b>37 (74)</b>
<b>Own house</b>	45 (90)	Wife/husband	7 (14)
<b>Rented house</b>	5 (10)	Mother/father	2 (4)
		In-law	2 (4)
		Self	2 (4)
<b>Wage earner</b>		<b>Current Occupation</b>	<b>28 (56)</b>
<b>Yes</b>	16 (32)	Unemployed	4 (8)
<b>No</b>	34 (68)	Farmer Shopkeeper	7 (14)
		Small business	8 (16)
		Others	3 (6)

The income data shows that majority of the SCI patients had a monthly family income of 6000-10000 BDT (55.6%, n=25) followed by 11000-15000 BDT (17.8%, n=8) and then 1000-5000 (13.3%, n=6) (Fig-1).



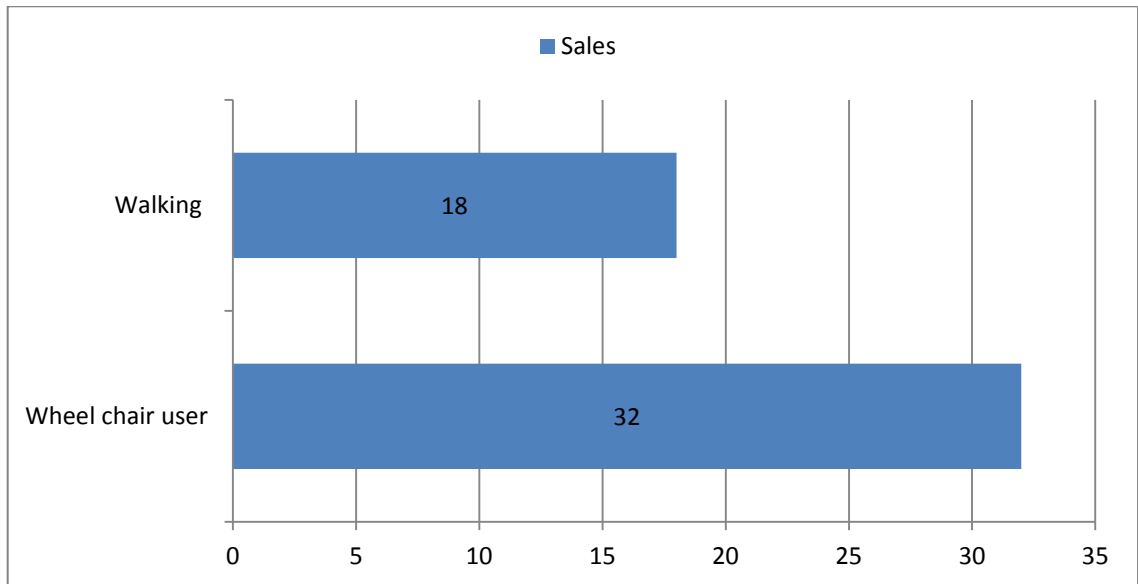
**Fig-4.1.2: Distribution of Monthly Family Income.**

Among the 50 (n=50) participants 30 participants were tetraplegia and 20 were paraplegia.



**Fig-4.1.3: Distribution of Type of Paralysis among the SCI Patient.**

Mobility assessment found that majority of the cases are wheelchair user (60%, n=30) during the study period.



**Fig-4.1.4:Mobility Status of SCI Patient.**



## 4.2 Respondents' Secondary Complication and Mortality

Out of 45 patients we found that Bowel dysfunction (64.4%) was the most common complication, followed by spasticity (59.9%), it means n=20 patient score was 1 out of 6, n=6 patients score was 2 out of 6 and n=1 patient score was 3 out of 6. Pain not related to overuse (44.4%). The least common complication was Injury caused by loss of sensation (2.2%).

**Table-4.2.1:** Distribution of Secondary Complications Show Average Point of '0' to '48'

Secondary Complications	Not experiences n (%)	Mild/ Infrequent n (%)	Moderate/ Occasional n (%)	Severe/ Chronic n (%)	Total (%)
1. Pressure ulcer(s)	39 (86.9)	3 (6.7)	3 (6.7)		13.4 %
2. Injury caused by loss of sensation.	44 (97.8)	1 (2.2)			2.2%
3. Muscle spasms (spasticity)	18 (40.0)	20 (44.4)	6 (13.3)	1 (2.2)	59.9 %

4. Contractures	40 (88.9)	3 (6.7)	2 (4.4)		11.1 %
5. Heterotopic bone ossification:	45 (100.0)				
6. Diabetes mellitus:	43 (95.6)	1 (2.2)	1 (2.2)		4.4%
7. Bladder dysfunction:	37 (82.2)	7 (15.6)	1 (2.2)		17.8 %
8. Urinary tract infections:	35 (77.8)	8 (17.8)	2 (4.4)		22.2 %
9. Bowel dysfunction:	16 (35.4)	18 (40.0)	11 (24.4)		64.4 %
10. Sexual dysfunction:	33 (73.3)	5 (11.1)	7 (15.6)		26.7 %
11. Autonomic dysreflexia:	43 (95.6)	2 (4.4)			4.4%
12. Postural	41 (91.1)	4 (8.9)	1 (2.2)		11.1

hypotension:					%
13. Circulatory problems:	27 (60.0)	17 (37.8)			37.8 %
14. Respiratory problems:	40 (88.9)	4 (8.9)	1 (2.2)		11.1 %
15. Pain not related to overuse:	25 (55.6)	15 (33.3)	5 (11.1)		44.4 %
16. Pain in muscles or joints related to overuse injuries:	43 (95.6)	2 (4.4)			4.4%

In this result we found the different between the socio-demographic status with the education, type of paralysis and mobility aids. We found in this result there is a different between the secondary complication such as pressure, spasticity and contracture Bowel dysfunction, Urinary tract infections bladder dysfunction has an different between the wheel chair user. Age ( $\geq 30$ ) has an different between the Contractures, Diabetes mellitus Heterotopic bone ossification. In here (**Table: 4.2.1**)

we found different between the contractures, Diabetes mellitus, bone ossification (Table: 4.2.1).

**Table-4.2.2: Cross tab Secondary Complication Data with Socio-Demographic Data, Type of Paralysis and Mobility Status.**

<b>Secondary Complications</b>	<b>Age (in year) n (%)</b>	<b>Sex n (%)</b>	<b>Education n (%)</b>	<b>Type of paralysis n (%)</b>	<b>Mobility status n (%)</b>
<b>1.Pressure ulcer(s):</b>	<35: 3(11.5)  ≥35: 8(33.3)	M:7 (17.5)	Illiterate: 1 (7.1)  Primary: 3 (20.0)  ≥Secondary : 2 (12.5)	Paraplegia : 5 (17.9)  Tetraplegia: a: 2 (11.1)	W/C user: 11 (36.7)*  Walking:  0 (0.0)
<b>2. Injury caused by loss of sensation:  Experienced  Not</b>	<35:1 (3.8)  ≥35: 5 (20.8)	M: 2 (5.0)	Illiterate: 0 (0.0)  Primary: 0 (0.0)  ≥Secondary : 1 (6.3)	Paraplegia : 2 (7.1)  Tetraplegia: a: 0 (0.0)	W/C user: 5 (16.7)  Walking: g: 1 (5.0)

<b>Experienced</b>					
<b>3. Muscle spasms (spasticity):</b>	<35:18 (69.2)	M: 26 (65.0)	Illiterate: 8 (57.1)	Paraplegia : 17 (60.7)	W/C user: 25 (78.1)*
<b>Experienced</b>	≥35:14 (58.3)	F: 2 (33.3)	Primary: 11 (73.3)	Tetraplegia a: 11 (61.1)	Walkin g: 7 (35.0)
<b>Not Experienced</b>			≥Secondary : 8 (50.0)		
<b>4.Contractures:</b>	<35:2 (7.7)** ≥35: 8 (33.3)	M: 6 (15.0)	Illiterate: 2 (14.3)	Paraplegia : 3 (10.7)	W/C user: 9 (30.0)**
<b>Experienced</b>			Primary: 1 (6.7)	Tetraplegia a: 3 (16.7)	Walkin g: 1 (5.0)
<b>Not Experienced</b>			≥Secondary : 2 (12.5)		
<b>5.Heterotopic bone ossification:</b>	≥35:5** (20.8)	M:1 (2.5)		Paraplegia : 3 (3.6)	W/C user: 5 (16.7)
<b>Experienced</b>					
<b>Not Experienced</b>					

<b>6.Diabetes mellitus:</b>	$\geq 35:7^{**}$ (29.2)	M:3 (7.5)	Illiterate: (7.1)	Paraplegia : 2 (7.1)	W/C user: 7 (23.3)
<b>Experienced</b>			$\geq$ Secondary : (6.2)	Tetraplegia: a: 1 (5.6)	
<b>Not Experienced</b>					
<b>7. Bladder dysfunction:</b>	$<35:5$ (19.2)	M: 8 (20.0)	Illiterate: 1 (7.1)	Paraplegia : 6 (21.4)	W/C user: 10 (30.3)**
<b>Experienced</b>	$\geq 35:$ 8 (33.3)	F: 1 (16.7)	Primary: 2 (13.3)	Tetraplegia: a: 3 (16.7)	Walkin g: 1 (15.0)
<b>Not Experienced</b>			$\geq$ Secondary : 5 (31.2)		
<b>8. Urinary tract infections:</b>	$<35:7$ (26.9)	M: 9 (22.5)	Illiterate: 2 (14.3)	Paraplegia : 8(28.6)	W/C user: 10(40.0) )*
<b>Experienced</b>	$\geq 35:$ 8 (33.3)	F: 2 (33.3)	Primary: 6 (40.0)	Tetraplegia: a: 3 (16.7)	Walkin g: 3 (15.0)
<b>Not Experienced</b>			$\geq$ Secondary: 2 (12.5)		
<b>9. Bowel dysfunction:</b>	$<35:17$ (65.4)	M: 27 (67.5)	Illiterate: 8 (57.1)	Paraplegia : 18(64.3)	W/C user: 24(80.0)

<b>Experienced</b>	≥35: 17 (70.8)	F: 3 (50.0)	Primary: 11 (73.3)	Tetraplegia: 12 (66.7)	)* Walkin g:10 (50.0)
<b>Not Experienced</b>			≥Secondary : 10 (62.5)		
<b>10. Sexual dysfunction:</b>	<35: 9(34.6) ≥35: 8 (33.3)	M: 12 (30.0) F: 1 (16.7)	Illiterate: 2 (14.3) Primary: 6 (40.0)	Paraplegia : 9(32.1) Tetraplegia: 4 (22.2)	W/C user: 9 (30.0) Walkin g:8 (40.0)
<b>Experienced</b>			≥Secondary : 4 (25.0)		
<b>Not Experienced</b>					
<b>11. Autonomic dysreflexia:</b>	<35: 2(7.7) ≥35: 5 (20.8)	M: 2 (5.0) F: 1 (16.7)	≥Secondary : 2 (12.5)	Paraplegia : 2(7.1) Tetraplegia: 1 (5.6)	W/C user: 6 (20.0) Walkin g:8 (40.0)
<b>Experienced</b>					
<b>Not Experienced</b>					
<b>12. Postural hypotension:</b>	<35: 3(11.5) ≥35: 6 (25.0)	M: 5 (12.5)	Illiterate: 2 (14.3)	Paraplegia : 4(14.3) Tetraplegia: 1 (5.6)	W/C user: 6 (23.3) Walkin g:8
<b>Experienced</b>			≥Secondary : 2 (12.5)		
<b>Not Experienced</b>					

					(10.0)
<b>12.Circulatory problems:</b>	<35: 11(42.3)	M: 18 (45.0)	Illiterate: 5 (35.7)	Paraplegia : 13(46.4)	W/C user: 22 (73.3) *
<b>Experienced</b>	≥35: 12 (50.0)	F: 1 (16.7)	Primary: 6 (40.0)	Tetraplegia: 6 (33.3)	Walking: 1 (5.0)
<b>Not Experienced</b>			≥Secondary : 7 (43.8)		
<b>14.Respiratory problems:</b>	<35: 2(7.7) *	M: 6 (15.0)	Illiterate: 3 (21.4)	Paraplegia : 3(10.7)	W/C user: 9 (30.0) *
<b>Experienced</b>	≥35: 8 (33.3)		≥Secondary : 2 (12.5)	Tetraplegia: 3 (16.7)	Walking: 1 (5.0)
<b>Not Experienced</b>					
<b>15.Pain not related to overuse:</b>	<35: 12(46.2)	M: 19 (47.5)	Illiterate: 4 (28.6)	Paraplegia : 12(42.9)	W/C user: 19 (63.3) *
<b>Experienced</b>	≥35: 13 (54.2)	F: 2 (33.3)	Primary: 8 (53.6)	Tetraplegia: 9 (50.0)	Walking: 6 (30.0)
<b>Not Experienced</b>			≥Secondary : 8 (50.0)		
<b>16.Pain in muscles or</b>	<35: 2(7.7)	M: 2 (5.0)	Primary: 1 (6.7)	Paraplegia : 2(7.1)	W/C user: 6
	≥35: 5				



<b>joints</b>	(20.8)	F: 1	≥Secondary	Tetraplegi	(20.0)*
<b>related to</b>		(16.7)	: 1 (6.2)	a: 1(5.6)	Walkin
<b>overuse</b>					g: 1
<b>injuries:</b>					(5.0)
<b>Experienced</b>					
<b>Not</b>					
<b>Experienced</b>					

\*p value is significant (<0.05) in Chi Square test

\*\*p value is significant (<0.05) in Fisher's Exact test

Distribution of secondary complications show average point of Mean of the secondary complication was 3.78 and Std. Deviation ± 2.95. From the analysis of the data was minimum 0 and maximum 12 (Table: 3)

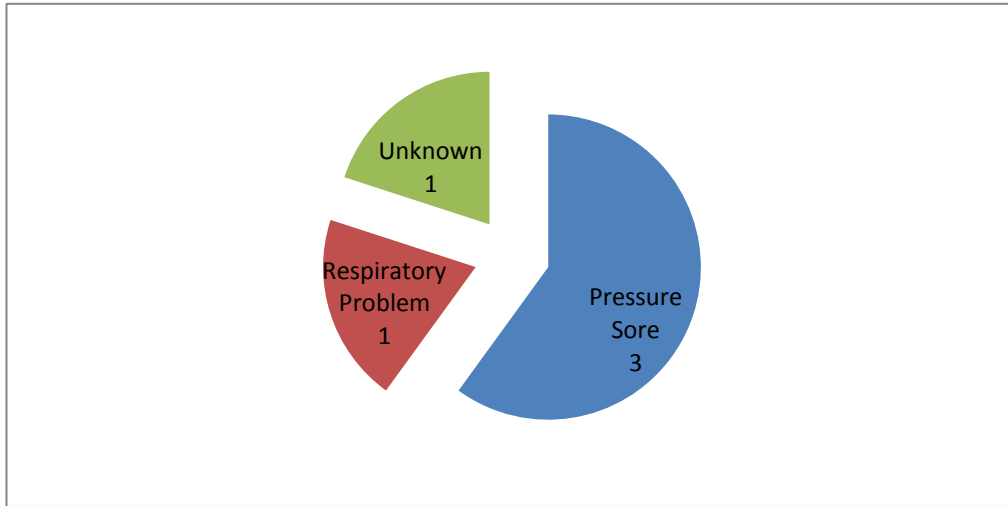
**Table: 4.2.3 Average Point of Mean of the Secondary Complication**

Out of 50 patient we found (10%, n=5) patient died in the community, in this (n=5)

Total patient	45	patient 3 patient
Mean	3.87	died due to
Std. Deviation	2.951	pressure sore
Maximum	12	and one died
		respiratory
		complication.

Other one patient cannot found the appropriate reason from their caregiver.

Three patients Died due to Pressure Sore out of Five, where One Patient Died as a Result of Respiratory Complication.



**Fig-4.2.4:Mortality Rate due to Secondary Complications**

### **4.3 Responds Psychological Status and Quality of Life.**

For measuring depression it was assessed by using the Centre for Epidemiologic Studies Depression Scale revised version (CESD-R). This instrument widely used to screen for depression and depressive disorders. It measures symptoms defined by the American Psychiatric Association Diagnostic and Statistical Manual (DSM-IV) for a major depressive episode. It was chosen because it has previously been used in Bangladesh and is available in Bangla the questionnaire contains 20 items each scored on a 4-point scale anchored at one end by 'rarely or none of the time (less than 1 day)' and at the other end by 'most or all of the time (5-7 days)'. Each item refers to emotions felt over the past week. Scores are tallied.

The highest possible score is 60 with higher scores indicative of more depressive symptoms. Responses were also analyzed to determine the number of participants with possible, probable and major depressive symptoms. These classifications were solely based on whether participants had reported experiencing any symptoms 'most or all of the time' in two, three or four of the following domains: sadness (questions 2, 4 and 6), loss of interest (questions 8 and 10), appetite (questions 1 and 18), sleep (questions 5, 11 and 19), thinking (questions 3 and 20), guilt (questions 9 and 17), fatigue (questions 7 and 16), agitation (questions 12 and 13) and suicidal ideation (questions 14 and 15). Among the 45 patients, the average depression score is 11.89 (11.89,  $\pm 4.21$ ) where the minimum score is 7 and the maximum is 26.

Distribution of Depression Scale revised versions show average point of Mean of the secondary complication was 11.89 and Std. Deviation  $\pm$  4.212. Here SD is half of mean so is trusted. From the analysis of the data was minimum 7 and maximum 26 (Table-4.3.1).

**Table 4.3.1: Depression Scale Revised Versions show Average Point of Mean**

Total patient	45
Mean	11.89
Median	10.00
Std. Deviation	4.212
Range	19
Minimum	7
Maximum	26

15 imply no clinical significance, 15 to 21 interprets mild to moderate depression and more than 21 states the possibility of major depression. Majority (77%, n=35) of the subjects did not experienced any clinical sign of depression. Only a few patients (4.4%, n=2) had possibility of major depression (Table: 4.3.2).

**Table 4.3.2 : Cross-tab Analysis Depression Scale with Socio-demographic Data, Education Type of Paralysis and Mobility of Status.**

<b>Level of depression</b>	<b>All Participants</b>	<b>Age (in Year)</b>	<b>Sex</b>	<b>Education</b>	<b>Type of paralysis</b>	<b>Mobility status</b>
	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)
<b>No clinical significance (Less than 15)</b>	35 (77.8)	<35: 21 (80.8) ≥35: 14 (58.3)	Male: 31 (77.5) Female: 4 (66.7)	Illiterate: 11 (78.6) Primary: 13 (86.7) Secondary & above: 11 (68.8)	Paraplegia: 21 (75.0) Tetraplegia: 4 (77.8)	Yes: 16 (53.3) No: 19 (95.5)

Mild to Moderate Depression (15-21)	8 (17.8)	<35: 4 (15.4) ) ≥35: 4 (16.7) )	Male: 7 (17.5)  Femal e 1 (16.7)	Illiterate: 3 (21.4)  Primary: 1 (6.7)  Secondar y & above: 4 (25.0)	Paraplagia: 6 (21.4%)  Tetraplagia: 2 (11.1)	Yes: 7 (23.3)  No: 1 (5.0)
Possibility of Major Depression (over 21)	2 (4.4)	<35: 1 (3.8) ) ≥35: 6 (25.0) )	Male: 2 (5.0)  Femal e 1 (16.7)	Primary: 1 (6.7)  Secondar y & above: 1 (6.2)	Paraplagia: (3.6)  Tetraplagia: 2 (11.1)	Yes: 7 (23.3)

\*p value is significant (<0.05) in Chi Square test

\*\*p value is significant (<0.05) in Fisher's Exact test

#### 4.4 Level of Depression

There was 77.8% had no significance of clinical depression, 17.8 % had moderate depression and only 4.4% had major depression.

**Table-4.4.1: Distribution of Level of Depression**

Level of depression	n (%)
No clinical significance (Less than 15)	35 (77.8)
Mild to Moderate Depression (15-21)	8 (17.8)
Possibility of Major Depression (over 21)	2 (4.4)

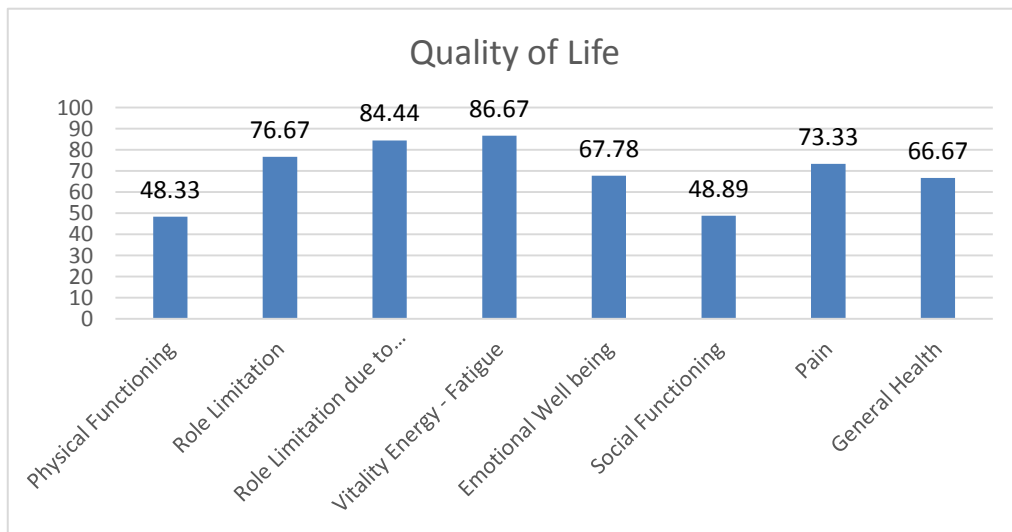
**4.5: Health-Related Quality of Life will be Self-assessed Using the Short Form Health Survey-12 (SF12) Questionnaire.**

This is a standardized assessment of QOL. It comprises 12 questions that are rated on a 2–6-point scale depending on the question. It has been translated into Bangla, and both this and the longer SF36 have been used previously in Bangladesh. The Physical Component Summary and the Mental Component Summary scores were obtained using the standard procedure. Higher scores indicate better QOL. Scores were standardized so that 50 represented average functioning and the s.d. was 10 (that is, a score of 30 is equivalent to the lowest 2% of the American population).



#### 4.5 Quality of life (SF12v2):

This figure shows the quality of life of the SCI participants according to physical functioning, role limitation, role limitation due to emotional problem, vitality energy fatigue, emotional well-being, social functioning, pain and general health.



**Fig-4.5.1: Distribution of Domains of Quality of Life.**

#### 4.6. Mental QoL Domain Scores

The mean and standard deviation of physical function of mental QoL score were 48.33 and 35.91. The mean and standard deviation of role limitation of mental QoL score were 76.67 and 39.31. The mean and standard deviation of role limitation due to emotional problem of mental QoL score were 84.44 and 35.07. The mean and standard deviation of fatigue mental QoL score were 86.67 and 22.36.

**Table-4.6.1: Mean and Standard Deviation of Physical QoL Domain Scores.**

	<b>Physical Functioning</b>	<b>Role Limitation</b>	<b>Role Limitation due to Emotional Problem</b>	<b>Vitality Energy – Fatigue</b>
<b>Mean</b>	48.33	76.67	84.44	86.67
<b>Std. Deviation</b>	35.91	39.31	35.07	22.36

The mean and standard deviation of emotional well-being of mental QoL score were 67.78 and 17.37. The mean and standard deviation of social function of mental QoL score were 48.89 and 22.59. The mean and standard deviation of pain physical of mental QoL score were 73.33 and 42.10. The mean and standard deviation of general health of mental QoL score were 66.67 and 26.11.

**Table-4.6.2: Mean and Standard Deviation of Mental QoL Domain Scores**

	Emotional Well being	Social Functioning	Pain	General Health
Mean	67.78	48.89	73.33	66.67
Std. Deviation	17.37	22.59	42.10	26.11

## Physical QoL and Mental QoL

The mean score of physical and mental health of QoL domain score was 66.25 and 71.94.

**Table-4.6.3: Comparison of Means of Physical and Mental QoL Domain Scores.**

Statistics		
	Physical Health	Mental Health
Mean	66.25	71.94

- Physical health summary: 66.25, Physical health score is slightly above the average.
- Mental Health summary: 71.94, mental health score is well over average.

### Physically:

- Role limitation is better than most.
- Pain situation is also better than other physical domains
- Physical Functioning is below average range

### Emotionally:

- Vitality is better than other emotional domains.
- Performance of work, home and school activities is more limited

**4.7 WHODAS – v2 – Participation Items:** The World Health Organization Disability Assessment Scale (WHODAS)—Participation Items (V2.0). This is a standardized assessment of participation, chosen because it has previously been used successfully in Bangladesh and is available in Bangla. It consists of eight questions each rated on a 5-point scale with the following anchors: ‘none’, ‘mild’, ‘moderate’, ‘severe’ and ‘extreme (or cannot do)’. The self-administered version was used even though the questions were read out over the phone. Scores are tallied to provide an overall score with a total possible score of 40 where 0 represents no problems with community participation and 40 represents extreme problems with participation.

From the distribution of Community Participation Scale Revised Version show Average Point of Mean is 12.00 and Std. Deviation  $\pm$  7.148.

**Table-4.7.1: Distribution of Community Participation Scale Revised Version**

All participant	
Mean	12.00
Median1	4.00
Std. Deviation	7.148

The WHODAS scale identified that majority of the respondents (75.6%, n=34) had some level of difficulties in participation. Maximum subjects (26.7%, n=12) had mild level of difficulties as compared to only 4.4% (n=02) had extreme level of difficulties in participation (Table-10).

**Table-4.7.2:Distribution of Score Found in the WHODAS Scale.**

Level of difficulties in Participation	Number	Percentage
None	11	24.4%
Mild	12	26.7%
Moderate	11	24.4%
Severe	09	20.1%
Extreme or cannot do	02	4.4%

### 5.1 Introduction

When Spinal cord injury happened through traumatic incident such as road traffic accident or a fall from high, the transition is often from good health to permanent disability, whether the origin is traumatic or non-traumatic, now days it can be preventable.

Primary prevention involves actions to avoid or remove the cause of SCI in an individual or a population before the problem arises. Such as actions to reduce road traffic injuries should be careful about during climbing the tree or any high area. Secondary prevention comes into non traumatic SCI has occurred in that time we should provide early diagnosis and treatment. We can also improve the knowledge about SCI related and its secondary complication.

In here we calculate only 50 patient among them 5 patient were died as because of pressure, respiratory problem and other cause. Most of the patient are illiterate and mostly suffer from different secondary condition such as bowel problem, circulatory problem muscle spasticity. We found the less activity physical and as well social work in the community. Physical activity is less than average.

There is very strong relation between physical exercises with quality of life for the Spinal cord injury patient. Less of physical exercise is decrease the quality of life for the patient with Spinal cord Injury, not only the physical activity, age and gender also weakly related to quality of life. Lack of participation in the community, limitation of the activity and secondary complication is also hampering QOL for the patient with SCI (Vaidyanathan, et al., 2001) (Lude, et al., 2014).

Expectancy of life is now high in the devolving country as because of medicine, prevention and treatment, including early acute management of and long term rehabilitation (DeVivo, et al. 1999) in the other hand survival rate has improved also for individuals with SCI in low income countries, the mortality rate is still high and life expectancy is significantly lower than amongst the general population (Levy,et al. 1998).

In our study, we found 10% died after five years of discharge from the hospital. Austria reported an average crude mortality rate of 4.1 and an age-standardized mortality rate of 2.38 (95% CI: 1.61 to 6.63) per million for the period of 2002–2012 (Majdan, et al., 2017).Our sample size is 50 out of 295 patients.

In the high income countries significant improvements in the management of urologic issues and the prevention and treatment of pressure sores have shifted the leading causes of death to heart and cardiovascular diseases and respiratory complications. This shift in leading causes of death was not identified for low income countries, and in Zimbabwe septicemia because of urinary tract infections and pressure sores and pneumonia had the greatest impact on life expectancy (Levy,et al. 1998).

In Bangladesh we found Pressure ulcer is the main cause of the premature death and specialized service in Bangladesh indicate that 19% of people with SCI who are wheelchair-dependent and survive until discharge, die within two years (Hossain, et al., 2015). In Bangladesh, 2015, Causes of death are shown the most common cause of death prior to discharge was respiratory failure (n=13/21, 62%). The most common cause of death after discharge was sepsis due to pressure ulcers (n=30/54, 56%) (Hossain, et al., 2015), septicemia because of urinary tract infections and



pressure sores and pneumonia had the greatest impact on life expectancy (Qderud, 2014).

Out of five we found three patients died due to pressure sore. In low meddle encomia country, also revealed that urinary tract infections and infectious pressure sores are frequently causing major health problems amongst people with SCI, possibly still being the leading cause of death.

A high prevalence of pressure sores and pain after returning home was documented along with the need for wheelchairs (Levy,et al. 1998). In our study we found pain out of more than half of our sample size. In the low meddle income country Pain, and depression was reported to have a major impact on the quality of life of people with SCI, both from the literature (Ravenscroft,et al. 2000).

We found here form the demographic history that structural poverty in a society degrades the situation for people with SCI. it creating barriers, thereby increasing the risk of contracting harmful infections and pressure sores, and increasing mortality. The majority of the informants had a limited income because of losing their jobs and not receiving any financial support. Productive activity improves their quality of life such as activity or any kind of leisure work. Productive activity, responsibility controlling over the life as well as meaning full activity improve quality of life for the individuals of patient with SCI. Environment is depends on few more area such as financial support, freedom, physical safety, security, health and social care, home environment, participation in and opportunities for the recreation or in leisure activities, transport, so all the components is needed for the better QOL (Kumar and Gupta, 2016). Unemployed has a high effect on the QOL, After SCI medical management is bit expensive for the patient with spinal cord injury. Use of catheterization is also important in the daily basis. Urinary infection is the more

common problem as because of unclean catheterization. Prolong or frequent urinary infection followed by kidney damage is one of the early mortality causes (Silver, 2010)

The study showed that SCI is male predominant (90%) which was consistent with the findings among the other available literatures but only (Lim, et al., 2017) has found on the contrary where majority of the respondents were female (53.60%). In Bangladesh, (Arafat et al., 2017) mention that, through 150 participants, most of the participants (30%) had moderately severe depression, 28% had moderate depression, 25.33% had mild depression, 10.66% had minimal depression, and 6% had severe depression. Here we found in our finding mild to moderate depression 17%, and severe depression is 4.4%.

They also experienced a lack of appropriate wheelchairs and affordable medical devices (catheter, urinary bags, etc.), limited access to public transport and education, limited social participation, mental stress from family and society. These are all contributing factors reducing the quality of life and contributing to the mortality of people with SCI. Affordability and accessibility of services and devices, less prejudice and increased social participation might help facilitating survival of individuals with SCI. Although the survival rate has improved also for individuals with SCI in low income countries, the mortality rate is still high and life expectancy is significantly lower than amongst the general population (Qderud, 2014). In japan 2004, The average age of injury was 30.1 and standard deviation (SD) was 9.2 years old, the average age of initial entry into the centers was 36.9 (SD=10.1) years old. In British hospitals (2009) total fatalities were 118, and average age of death was 54.6 (SD=10) years old. Average duration from the time of injury to entrance into the

centers was 6.8 years, so the cumulative survival rate of persons with SCI who exceeded the average of 6.8 years after injury was calculated (Imai, et al., 2004).

In the UK the two most prominent underlying causes of death were diseases of the circulatory system (40%) and diseases of the respiratory system (24%) (Krause & Carter, 2009). We also found the majority of the patient suffers from the circulatory system and few are suffer from respiratory problem. Pain, boredom and depression were reported to have a major impact on the quality of life of people with SCI, both from the literature (Levy, et al. 1998).

Environmental factors are important predictors of mortality after SCI (Krause and Carter, 2009). In our finding 80% leave in the village, on their own house and 5% stay in the city with rent a house. It is very much important to go outside of the house; here we found majority of the patient did not go out of the house, as because of environment is not appropriate for me wheel chair. We found 61% patient is wheel chair dependent, 38% patient does not use wheel chair but they need other walking device.

Friendly environment might be conveying for patient with Spinal cord injury. Many study reported, how the environment affects perceived quality of life for patient with spinal cord injury. Unfriendly environment is also reported low quality of QOL for patient with SCI (Lude, et al., 2014). In low middle income country it is very important to cope with challenges for person of Spinal cord injury patient especially for the tetra patient. Challenge is different in the community such as physical, social, environmental and most importantly psychological levels (Lude, et al., 2014). We found accessibility problem is everywhere in low middle income country.

We found in our study patient who use wheel chair in the community was not attend their social program. Poverty makes life even harder for people with SCI (Kelly and

Vogel, 2013). Poverty is the main problem; poverty might accelerate the severity of disability after SCI. in our finding only 26.7% patient 6000-10000 per month without support of family member, among them 35% are walking patient from total count.

### 6.1 Conclusion

SCI is largely predictable and preventable. Research and development over the past many years has resulted in interventions established to reduce incidence of SCI from variety of causes like fall from high, road traffic accident and violence and early diagnosis from pathological cause. We found secondary complication that hampered life expectation not only in the low middle income country but also in the developed country. All the developed countries try to minimize the incidence but it still remains all around the world. In the developing countries it is more devastating, sometime it is very much costly to prevent the secondary complications in the low middle income countries.

The study indicates that life expectancy for individuals with SCI in low income settings is shorter than for the average population. It is found that most of the patients were using wheelchair for mobility and majority of them were paraplegic patients.

Study revealed that majority of the patients were suffering from some kind of secondary complications such as bowel dysfunction, spasticity, chronic pain not related to overuse, circulatory problems and sexual dysfunctions. Only a few patients were suffering from injury due to loss of sensation, autonomic dysreflexia, diabetes mellitus and pain related to overuse. It has been also found that a very few patients died in the community due to secondary complication. Based on the findings of the studies it is found that almost every patient is suffering from any kind of secondary complications. So it is needed to improve availability of medical services in the community for this kind of patients to prevent life threatening

complications. Majority of the participants had no clinical sign of depression but only few had the possibility of major depression.

Study found that physical functioning of the participants was below the average level. So measures can be taken to improve their performance of work, home and social activities. Study also revealed that maximum participants had mid-level of difficulties in community participation. So measures can be taken to improve their community participation which may improve their quality of life and life expectancy.

## **6.2 Recommendation**

The following recommendations will be more helpful to prevent the secondary complications of SCI patients after discharge from hospital and to improve their quality of life.

- Community base intervention will be improved survival after discharge form hospital for LMIC.
- Low-cost model of community- base model support can improve the QOL or depression.
- Need educated about skin care. Possibly, patients require about skin care education and support after discharge that will be prevent PU and other secondary complication.
- Data will be more accurate if we collect from the community, there will be less chance to miss the information, and we can see the facial expression of the patient during interview time.
- Community people need up-to-date knowledge and information about SCI and its prevention. Although the attitude level was neutral and the practice level was moderate, the knowledge level was also moderate.
- As caregiving is a difficult job especially for long term conditions like SCI it develops psychological stress among caregivers. So adequate knowledge should be provided to care givers which will assist them to cope with the stress and enhance the quality of their life and their patients.
- Promoting a positive attitude and addressing personal and behavioral factors are important for proper care of the affected individual.

Adequate knowledge if adequate knowledge is provided to general population then it will assist them to cope with the stress and develop positive attitude towards Spinal Cord Injury.



### **6.3 Strengths and Limitations of the Study**

#### **Strengths of the Study**

We can collect the entire fifty patient not only the by phone but also the doing home visit in different area of the Bangladesh. Every patient joins spontaneously. It was very difficult to explain patient by phone about our questionnaire bur research manage this.

#### **Limitations of the Study**

Time was very limited for this type of research and also data was also a short, it is only 50. Another limitation was the generalizability of the findings because this study was conducted in one rehabilitation center. The findings may not be generalized to other rehabilitation centers. The fact that no study was conducted so far in Bangladesh on this topic; no enough literature was available to discuss in national context.

### **6.4 Suggestions for Future Research**

This study is not collect full of data in 2011, as because of time limitation, so further research will be held in this area with full of data.

Allotey, P., Reidpath, D., Kouamé, A. and Cummins, R. (2003). The DALY, context and the determinants of the severity of disease: an exploratory comparison of paraplegia in Australia and Cameroon. *Social Science & Medicine*, 57(5), pp.949-958.

Amarin, Z. and Obeidat, A. (2010). Effect of folic acid fortification on the incidence of neural tube defects. *Paediatric and Perinatal Epidemiology*, 24(4), pp.349-351.

Anon, (2018). [online] Available at: <http://dx.doi.org/10.1089/neu.2004.21.1355> [Accessed 20 May 2018].

Arora, M., Harvey, L., Lavrencic, L., Bowden, J., Nier, L., Glinsky, J., Hayes, A. and Cameron, I. (2015). A telephone-based version of the spinal cord injury–secondary conditions scale: a reliability and validity study. *Spinal Cord*, 54(5), pp.402-405.

Barman, A., Shanmugasundaram, D., Bhide, R., Viswanathan, A., Magimairaj, H., Nagarajan, G., Arumugam, E., Tharion, G. and Thomas, R. (2014). Survival in Persons With Traumatic Spinal Cord Injury Receiving Structured Follow-Up in South India. *Archives of Physical Medicine and Rehabilitation*, 95(4), pp.642-648.

Breithaupt DJ, JousseAT, Wynne-Jones M. Late causes of death and life expectancy in paraplegia. *The Canadian Medical Association Journal* 1961; 85: 73-77.

Burns, A. and O'Connell, C. (2012). The challenge of spinal cord injury care in the developing world. *The Journal of Spinal Cord Medicine*, 35(1), pp.3-8.

Burns, A. and O'Connell, C. (2012). The challenge of spinal cord injury care in the developing world. *The Journal of Spinal Cord Medicine*, 35(1), pp.3-8.

Chappel, P.,Wirz, S., 2003, quality of life following spinal cord injury for 20-40 years old male living in Srilanka. *Asia pacific rehabilitation journal* 14(2),162-178. February 2003.

De Vivo MJ et al. Causes of death for patients with spinal cord injuries. *Arch Internal Med* 1989; 149: 1761- 1766.

DeVivo, M. (1997).Causes and costs of spinal cord injury in the United States.*Spinal Cord*, 35(12), pp.809-813.

DeVivoMJ,KrauseJS,Lammertse DP (1999) Recent trends in mortality and causes of death among persons with spinal cord injury. *Arch Phys Med Rehabil* 80, 1411–9.

Disability in Bangladesh, 2002. Impact foundation.<http://www.impactfoundationbd.org/>.

Ebrahimzadeh, M., Shojaei, B., Golhasani-Keshtan, F., Soltani-Moghaddas, S., Fattahi, A. and Mazloumi, S. (2013). Quality of life and the related factors in spouses of veterans with chronic spinal cord injury.*Health and Quality of Life Outcomes*, 11(1), p.48.

Fehlings, M., Singh, A., Tetreault, L., Kalsi-Ryan, S. and Nouri, A. (2014). Global prevalence and incidence of traumatic spinal cord injury.*Clinical Epidemiology*, p.309.

Foote, J. (2003). Sex, Sexuality, and Fertility for Women with Spinal Cord Injury.*Topics in Spinal Cord Injury Rehabilitation*, 8(3), pp.20-25.

Groce, N.E., (1999). An overview of young people living with disabilities: Their needs and their rights. PhD. Yale School of Public Health.

H. Elshahidi, M., Y. Monir, N., A. Elzhery, M., A. Sharaqi, A., Haedaya, H., I. Awad, B. and Zaghoul, K. (2018). Epidemiological Characteristics of Traumatic Spinal Cord Injury (TSCI) in the Middle-East and North-Africa (MENA) Region: A

Systematic Review and Meta-Analysis. *Bulletin of Emergency and Trauma*, 6(2), pp.75-89.

Hartkopp, A., Brønnum-Hansen, H., Seidenschnur, A. and Biering-Sørensen, F. (1997). Survival and cause of death after traumatic spinal cord injury. A long-term epidemiological survey from Denmark. *Spinal Cord*, 35(12), pp.862-864.

Hoque, F., Grangeon, C., and Reed, K., (1999). Spinal cord lesions in Bangladesh: an epidemiological study 1994-1995. *Spinal Cord*, 37:858-861.

Hoque, F., Grangeon, C., and Reed, K., (1999). Spinal cord lesions in Bangladesh: an epidemiological study 1994-1995. *Spinal Cord*, 37:858-861.

Hossain, M., Rahman, M., Herbert, R., Quadir, M., Bowden, J. and Harvey, L. (2015). Two-year survival following discharge from hospital after spinal cord injury in Bangladesh. *Spinal Cord*, 54(2), pp.132-136.

Howell, T., Fullerton, D., Harvey, R. and Klein, M. (1981). Depression in spinal cord injured patients. *Paraplegia*, 19(5), pp.284-288.

IMAI, K., KADOWAKI, T. and AIZAWA, Y. (2004). Standardized Indices of Mortality among Persons with Spinal Cord Injury: Accelerated Aging Process. *INDUSTRIAL HEALTH*, 42(2), pp.213-218.

Jica, 2002. Country profile on disability people republic of Bangladesh. <http://www.jica.go.jp/bangladesh/english/>.

Kalpakjian, C., Bombardier, C., Schomer, K., Brown, P. and Johnson, K. (2009). Measuring Depression in Persons With Spinal Cord Injury: A Systematic Review. *The Journal of Spinal Cord Medicine*, 32(1), pp.6-24.

Kelly, E. and Vogel, L. (2013). Overview of Psychosocial Health Among Youth with Spinal Cord Injury. *Topics in Spinal Cord Injury Rehabilitation*, 19(2), pp.129-141.

Krause, J. and Carter, R. (2009). Risk of mortality after spinal cord injury: relationship with social support, education and income. *Spinal Cord*, 47(8), pp.592-596.

Krause, J., Carter, R., Pickelsimer, E. and Wilson, D. (2008). A Prospective Study of Health and Risk of Mortality After Spinal Cord Injury. *Archives of Physical Medicine and Rehabilitation*, 89(8), pp.1482-1491.

Levy, L., Makarawo, S., Madzivire, D., Bhebhe, E., Verbeek, N. and Parry, O. (1998). Problems, struggles and some success with spinal cord injury in Zimbabwe. *Spinal Cord*, 36(3), pp.213-218.

Lim, S., Shiue, Y., Ho, C., Yu, S., Kao, P., Wang, J. and Kuo, J. (2017). Anxiety and Depression in Patients with Traumatic Spinal Cord Injury: A Nationwide Population-Based Cohort Study. *PLOS ONE*, 12(1), p.e0169623.

López-Camelo, J., Castilla, E. and Orioli, I. (2010). Folic acid flour fortification: Impact on the frequencies of 52 congenital anomaly types in three South American countries. *American Journal of Medical Genetics Part A*, 152A(10), pp.2444-2458.

Maharaj, J.C., (1996). Epidemiology of spinal cord paralysis in Fiji: 1985 – 1994. *Spinal Cord*, 34:549-559.

Majdan, M., Plancikova, D., Nemcovska, E., Krajcovicova, L., Brazinova, A. and Rusnak, M. (2017). Mortality due to traumatic spinal cord injuries in Europe: a cross-sectional and pooled analysis of population-wide data from 22 countries. *Scandinavian Journal of Trauma, Resuscitation and Emergency Medicine*, 25(1).

Marulappa, V.G., Manjunath, R., Mahesh, N., and Maligegowda, L., (2012). A Ten Year Retrospective Study on Adult Tetanus at the Epidemic Disease (ED) Hospital,

Mysore in Southern India: A Review of 512 Cases. *Journal of Clinical and Diagnostic Research*, 6(8):1377-1380.

Mock, C. (2008). Child injuries and violence: the new challenge for child health. *Bulletin of the World Health Organization*, 2008(6), pp.420-420.

Moshi, H., Sundelin, G., Sahlen, K. and Sörlin, A. (2017). Traumatic spinal cord injury in the north-east Tanzania – describing incidence, etiology and clinical outcomes retrospectively. *Global Health Action*, 10(1), p.1355604.

New, P. and Marshall, R. (2013). International Spinal Cord Injury Data Sets for non-traumatic spinal cord injury. *Spinal Cord*, 52(2), pp.123-132.

New, P.W. and Sundararajan, (2008). Incidence of non-traumatic spinal cord injury in Victoria, Australia: a population-based study and literature review. *Spinal Cord*, 46:406-411.

Nielsen, M. (2003). Post-traumatic stress disorder and emotional distress in persons with spinal cord lesion. *Spinal Cord*, 41(5), pp.296-302.

Ning et al 2011, Epidemiology of traumatic spinal cord injury in Tianzing, China, *spinal cord* ,vol.49, 386-390.

Ning, G., Yu, T., Feng, S., Zhou, X., Ban, D., Liu, Y. and Jiao, X. (2010). Epidemiology of traumatic spinal cord injury in Tianjin, China. *Spinal Cord*, 49(3), pp.386-390.

Øderud, T. (2014). Surviving spinal cord injury in low income countries. *African Journal of Disability*, 3(2).

Rahman, Z., Alam, S., Goni, M., Ahmed, F., Tawhid, A. and Ahmed, M. (2018). Demographic Profile of Spinal Cord Injury Patients Admitted in a Rehabilitation Centre: An Observational Study from Bangladesh. *Journal of Medical Research and Innovation*, p.e000111.

Rathore, F., Mansoor, S., Bin Qureshi, S., Burns, A. and O'Connell, C. (2012). Re: Burns AS, O'Connell C. The challenge of spinal cord injury care in the developing world. *J Spinal Cord Med.* 2012; 35:3–8. *The Journal of Spinal Cord Medicine*, 35(4), pp.194-196.

Razzak, A., Helal, S. and Nuri, R. (2011). Life Expectancy After Spinal Cord Injury In a Developing Country-A Retrospective Study At CRP, Bangladesh. *Disability, CBR & Inclusive Development*, 22(2).

Rose, J. (2012). Lessons for spinal cord injury rehabilitation taken from adult developmental psychology: 2011 Essie Morgan Lecture. *The Journal of Spinal Cord Medicine*, 35(3), pp.133-139.

Sezer, N. (2015). Chronic complications of spinal cord injury. *World Journal of Orthopedics*, 6(1), p.24.

Shingu, H., Ohama, M., Ikata, T., Katoh, S., and Akatsu, T., (1994). Spinal cord injuries in Japan: a nationwide epidemiological survey in 1990. *Paraplegia*, 32:3-8.

Shingu, H., Ohama, M., Ikata, T., Katoh, S., and Akatsu, T., (1994). Spinal cord injuries in Japan: a nationwide epidemiological survey in 1990. *Paraplegia*, 32:3-8.

Shingu, H., Ohama, M., Ikata, T., Katoh, S., and Akatsu, T., (1995). A nationwide epidemiological survey of spinal cord injuries in Japan from January 1990 to December 1992. *Paraplegia*, 33:183-188.

Soden, R., Walsh, J., Middleton, J., Craven, M., Rutkowski, S. and Yeo, J. (2000). Causes of death after spinal cord injury. *Spinal Cord*, 38(10), pp.604-610.

Soden, RJ., Walsh, J., Middleton, JW., Craven, ML., Rutkowski, SB., Yeo, JD., (2000). Causes of death after spinal cord injury. *Spinal Cord* 38(10), pp-604-610.

Stover, S.L. and Fine, P.R., (1987). The Epidemiology and Economics of Spinal Cord Injury. *Paraplegia*, 25:225-228.

WhalleyHammell, K. (1992). Psychological and sociological theories concerning adjustment to traumatic spinal cord injury: the implications for rehabilitation. *Paraplegia*, 30(5), pp.317-326.

World Health Organization (WHO), 2010, *Injuries and violence: The facts*, viewed 15 December 2010, from [http://whqlibdoc.who.int/publications/2010/9789241599375\\_eng.pdf](http://whqlibdoc.who.int/publications/2010/9789241599375_eng.pdf)

Wyndaele, M. and Wyndaele, J. (2006). Incidence, prevalence and epidemiology of spinal cord injury: what learns a worldwide literature survey?. *Spinal Cord*, 44(9), pp.523-529.



**ANNEX I: Informed consent (English)**  
**Information Sheet & Consent Form**

You are invited to take part in a research study titled:

**“An Evaluation of Spinal Cord Injury Patients at the end of five years after discharge from CRP”**

I am Md. AkhlasurRahman a student of Dhaka University, currently pursuing Master degree in the Rehabilitation Science at Bangladesh Health Professional Institute and conducting a master thesis under the supervision of Prof. Dr. Md. AlamgirKabir at Centre for the Rehabilitation of the Paralysed (CRP).

It is important to understand how people who are discharged from CRP manage in the community. Yet we have very little information about this. In particular, we want to know if patients have complications and if any of our patients have unfortunately died. There are two aims of this study. Firstly, to determine if any patients discharged from CRP in 2011 has died. Secondly, to determine the type and severity of complications other patients discharged in 2011 may have. Participation in this study is voluntary. The phone interview will take approximately 20 minutes.

We hope this study will provide us with information about outcomes in people with spinal cord injuries following discharge from CRP, your participation in this study may not be of direct benefit to you. However, there are no additional risks of being involved in this study. All aspects of the study, including results, will be strictly confidential and only me and research staff involved in the study will have access to your information. All data will be coded and stored on computer discs by the researchers for 12 years, at which time the files will be destroyed.

Participation in this study is entirely voluntary, they are not obliged to participate and they can withdraw at any time. Whatever their decision, it will not affect participation existing or future relationship with CRP or its staff.

I/we have had the Participant Information Sheet read to me by phone and understand it.

**Verbal consent by phone provided by:** .....

[name]

Date:.....

Verbal consent by phone witnessed by:.....

[name]

Date:.....

**Name of phone interviewee:**.....

[name]

Date:

## ANNEX II: Informed consent (Bengali)

আমার গবেষণা প্রকল্পে আপনি আমন্ত্রিত।

### “An Evaluation of Spinal Cord Injury Patients at the end of five years after discharge from CRP in 2011”

আমি মোঃ এখলাছুর রহমান এম.এস.সি. রিহাবিলিটেশন সায়েন্স, বাংলাদেশ হেলথ প্রফেশনাল ইন্সটিটিউট (বিএইচপিআই), ঢাকা বিশ্ববিদ্যালয়ের একজন ছাত্র। স্নাতকোত্তর ডিগ্রী প্রাপ্তির জন্য আমার একটি গবেষণা মূলক প্রকল্প পরিচালনা করা প্রয়োজন। যেটি আমি করছি প্রফেসর ড. আলমগীর কবির এর তত্ত্বাবধানে।

এটি খুবই গুরুত্বপূর্ণ জ্ঞান যে সি.আর.পি. থেকে ডিসচার্জ হওয়ার পরে তারা কীভাবে তাদের কমিউনিটিতে বাস করে? এ বিষয়ে খুবই কম ধারণা পাওয়া যায়। আমরা জানতে চাই রোগীদের বিভিন্ন ধরনের জটিলতা এবং তারা কীভাবে মারা যায়? এই গবেষণায় দুইটি উদ্দেশ্য আছে। প্রথমটি হচ্ছে ২০১১ সালে যে সকল রোগী ডিসচার্জ হয়েছেন তাদের মধ্যে কত জন রোগী মারা গিয়েছেন এবং দ্বিতীয়ত কত জন রোগী স্বাভাবিক জটিলতায় ভুগছেন। এই অধ্যয়নে আপনার অংশগ্রহণ ইচ্ছাকৃত এবং এর জন্য সাক্ষাতকার নিতে ২০ মিনিট সময় লাগতে পারে।

আমরা আশা করি এই গবেষণার ফলে আমরা জানতে পারবো ডিসচার্জের পরে রোগীদের কী ধরনের সমস্যা হয়। এই গবেষণায় আপনার অংশগ্রহণে আপনি কোন প্রকার উপকার পাবেন না এবং সাথে আপনার কোন অসুবিধাও হবে না। শুধু মাত্র গবেষণা আপনার এই তথ্যগুলো জানবেন এবং ১২ বছর পর্যন্ত সংরক্ষণ করে রাখবেন।

এই অধ্যয়নে আপনার অংশগ্রহণ ইচ্ছাকৃত এবং যে কোন সময় আপনি পত্যাচার করতে পারবেন এতে আপনার সাথে সি.আর.পি. সম্পর্কের কোন ধরনের ক্ষতিসাধন হবে না।

আমি এই সম্মতি পত্রটি পড়েছি এবং বুঝতে পেরেছি।

মোবাইলের মাধ্যমে মৌখিক সম্মতি : .....

তারিখ : .....

মোবাইলের মাধ্যমে স্বাক্ষরিত সম্মতি : .....

তারিখ : .....

সাক্ষাতকারীর নাম : .....

তারিখ : .....

**ANNEXIII: (English)**

**Questionnaire**

**RECORD of DEATH**

(please tick one only)

		Yes	No
Has the participant died?		<input type="checkbox"/>	<input type="checkbox"/>
Date of death:	_____ / _____ / _____ — day      month      year		
Date of death:	<input type="checkbox"/> Known and accurate <input type="checkbox"/> Not known but correct within 1 month <input type="checkbox"/> Not known but correct within 3 months <input type="checkbox"/> Not known but correct within 6 months <input type="checkbox"/> Not known but correct within 1 year <input type="checkbox"/> Not known and may be wrong by more than 1 year		
Cause of death:			
Who is telling you that the participant has died? Only provide details of relationship to participant (e.g. parent of participant, friend of participant). Do not provide name on this page.			
If you are relying on someone other than a family member to tell you that the participant has died – has a second and independent person confirmed that the person has died?	<input type="checkbox"/> yes <input type="checkbox"/> no		
If yes to above – who is the second person that is telling you that the participant has died (e.g. parent of participant, friend of participant). Do not provide name on this page.			
Please record any information given regarding the death of the participant:			

### Participant non-identifiable details

#### Marital Status:

(please tick one only)

<b>Q1a. What is your <u>current</u> marital status:</b> (please tick one only)	<input type="checkbox"/> Married <input type="checkbox"/> Not married <input type="checkbox"/> Separated / Divorced <input type="checkbox"/> Widowed
<b>Q1b. How many children do you have:</b>	
<b>Q1c. How many of these children were born more than 9 months after your SCI:</b>	

### Participant education, social and work details

These questions refer to the participant's current situation

<b>Q2a. Where do you <u>currently</u> live?</b> (please tick one only)	<input type="checkbox"/> Own house / parent's or family member's home <input type="checkbox"/> Renting house <input type="checkbox"/> Own flat /parent's or family member's flat <input type="checkbox"/> Renting flat <input type="checkbox"/> Slum Other: (please specify) _____ _____
<b>Q2b. When you were discharged were you living in a village or town?</b>	<input type="checkbox"/> Town – provide name _____ <input type="checkbox"/> Village– provide name _____

<p><b>Q3A. Since your injury, have you worked?</b></p> <p><b>Q3B. If yes, what was your position/job?</b></p>	<p><input type="checkbox"/> YES      <input type="checkbox"/> NO</p> <p>_____</p>
<p><b>Q4. What is your <u>current</u> work status? (please tick one only)</b></p>	<p><input type="checkbox"/> Full time employed (i.e., worked &gt;30 hours per week)</p> <p><input type="checkbox"/> Part time employed (i.e., worked &lt;30 hours per week)</p> <p><input type="checkbox"/> Retired</p> <p><input type="checkbox"/> Unemployed</p> <p><input type="checkbox"/> Home duties</p> <p><input type="checkbox"/> Student</p> <p><input type="checkbox"/> Volunteer</p> <p><input type="checkbox"/> None of the above (please specify) _____</p>
<p><b>Q5. What is your <u>current</u> income per month (in Taka)?</b></p>	<p>BDT _____</p>
<p><b>Q6. Are you <u>currently</u> the main income earner in your family?</b></p>	<p><input type="checkbox"/> YES      <input type="checkbox"/> NO</p>

<p><b>Q7. How many people <u>currently</u> live in your house with you?</b></p>	<p>Number of adults:</p> <p>Number of children:</p>
---	---

<p><b>Q8. How many other people in your household are <u>currently</u> in paid employment?</b></p>	
<p><b>Q9. What is the <u>current</u> combined income for your house per month (in Taka)? (This amount should include the participant's income).</b></p>	<p>BDT _____</p>

<b>Q10. Who is/are your main carer/s:(please tick as appropriate)</b>	Tick
Wife or husband	<input type="checkbox"/>
Mother or father	<input type="checkbox"/>
Grandparent	<input type="checkbox"/>
Daughter or daughter-in-law	<input type="checkbox"/>
Son or son-in-law	<input type="checkbox"/>
Sister	<input type="checkbox"/>
Brother	<input type="checkbox"/>
Paid person	<input type="checkbox"/>
Other (please specify)	<input type="checkbox"/>
Unknown	<input type="checkbox"/>

### Other details

<b>Q11. On discharge in 2011</b> - Did you require a wheelchair for mobility on a daily basis?	<input type="checkbox"/> yes	<input type="checkbox"/> no
--	------------------------------	-----------------------------

<b>Q12. Currently</b> - Do you require a wheelchair for mobility on a daily basis?	<input type="checkbox"/> yes	<input type="checkbox"/> no
--	------------------------------	-----------------------------

### CHECK OF DATA

<b>Q13.</b> Has the participant declined to answer any questions in this section	<input type="checkbox"/> yes	<input type="checkbox"/> no
<b>Q14.</b> If yes, please indicate which question they declines to answer and provide a reason. (eg Q4 – refused to answer; Q7 – even with prompting did not know how to answer).		

## SCI Secondary Conditions Scale

**Code:**

- 0 NOT experienced in the last 3 months or not a significant problem
- 1 MILD or INFREQUENT problem
- 2 MODERATE or OCCASIONAL problem
- 3 SEVERE or CHRONIC problem

*(put a tick in one box)*

*per item only)*

	0 Not experienced	1 Mild/ infrequent	2 Moderate/ occasional	3 Severe/ chronic
<b>Q1. Pressure ulcer(s).</b> This includes early signs of pressure ulcers or late stage pressure ulcers.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Q2. Injury caused by loss of sensation.</b> This includes burns from carrying hot liquids on the lap or sitting too close to a heater or fire.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Q3. Muscle spasms (spasticity).</b> This includes jerky involuntary movements in paralysed or partially paralysed muscles.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Q4. Contractures.</b> This includes loss of joint mobility that is present even when a joint is slowly stretched.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Q5. Heterotopic bone ossification.</b> This includes excessive laying down of bone. It is characterised by loss of joint mobility, local swelling and warmth at the area to the touch. This condition is diagnosed by a physician.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Q6. Diabetes mellitus.</b> Diabetes is a problem resulting from irregularities in blood sugar levels. Symptoms include frequent urination and excessive thirst. This condition is diagnosed by a physician.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Q7. Bladder dysfunction.</b> This includes problems related to incontinence, bladder or kidney stones, kidney problems, urine leakage and urine back up. NOTE: There is a separate item for urinary tract infections.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Q8. Urinary tract infections:</b> This includes infections such as cystitis and pseudomonas. Symptoms include pain when urinating, a burning sensation throughout the body, blood in the urine and cloudy urine.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	0 Not experienced	1 Mild/ infrequent	2 Moderate/ occasional	3 Severe/ chronic
<b>Q9. Bowel dysfunction:</b> This includes diarrhoea, constipation, incontinence and associated problems.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



	0 Not experienced	1 Mild/ infrequent	2 Moderate/ occasional	3 Severe/ chronic
<b>Q10. Sexual dysfunction:</b> This includes dissatisfaction with sexual functioning.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Q11. Autonomic dysreflexia:</b> Symptoms of dysreflexia include sudden rises in blood pressure and sweating, skin blotches, goose bumps, pupil dilation and headache.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Q12. Postural hypotension:</b> This involves a strong sensation of light headedness following a change in position. It is caused by a sudden drop in blood pressure.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Q13. Circulatory problems:</b> This includes swelling of the hands or feet, or blood clots.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Q14. Respiratory problems:</b> This includes respiratory infections or problems due to difficulties breathing, coughing or clearing secretions.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Q15. Pain not related to overuse.</b> This includes neuropathic or visceral pain or pain from any cause except overuse.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Q16. Pain in muscles or joints related to overuse injuries.</b> This includes pain in muscles or joints which is related to overuse (typically occurs in shoulders of people who are pushing manual wheelchairs a lot).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

<b>Q17. Additional question</b>	
<b>Do you currently have a pressure ulcer? (pls circle)</b>	Yes    No

**CHECK OF DATA**

Has the participant declined to answer any questions in this section	<input type="checkbox"/> yes	<input type="checkbox"/> no
If yes, please indicate which question they declines to answer and provide a reason. (eg Q4 – refused to answer; Q7 – even with prompting did not know how to answer).		

## WHODAS – v2 – Participation Items

**In the past 30 days:**

	None	Mild	Moderate	Severe	Extreme or cannot do
Q1. How much of a problem did you have in joining in community activities (for example, festivities, religious or other activities) in the same way as anyone else can?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q2. How much of a problem did you have because of barriers or hindrances in the world around you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q3. How much of a problem did you have living with dignity because of the attitudes and actions of others?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q4. How much time did you spend on your health condition, or its consequences?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q5. How much have you been emotionally affected by your health condition?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q6. How much has your health been a drain on the financial resources of you or your family?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q7. How much of a problem did your family have because of your health problems?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q8. How much of a problem did you have in doing things by yourself for relaxation or pleasure?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

### CHECK OF DATA

Has the participant declined to answer any questions in this section	<input type="checkbox"/> yes	<input type="checkbox"/> no
If yes, please indicate which question they declines to answer and provide a reason. (eg Q4 – refused to answer; Q7 – even with prompting did not know how to answer).		

## SF12 - Health Related Quality of Life

*Please answer every question. Some questions may look like others, but each one is different. Please take the time to read and answer each question carefully by filling in the bubble that best represents your response.*

Q1. In general, would you say your health is:GH

- Very good
- Good
- Poor

The following two questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

Q2. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf?  
PF

- Yes, limited a lot
- Yes, limited a little
- No, not limited at all

Q3. Climbing several flights of stairs. PF

- Yes, limited a lot
- Yes, limited a little
- No, not limited at all

During the past 4 weeks, have you had any of the following problems with your work or other regular activities as a result of your physical health?

Q4. Accomplished less than you would like? RP

- Yes
- No

Q5. Were limited in the kind of work or other activities? RP

- Yes
- No

During the past 4 weeks, have you had any of the following problems with your work or other regular activities as a result of any emotional problems (such as feeling depressed or anxious)?

Q6. Accomplished less than you would like? RE

- Yes
- No

Q7. Didn't do work or other activities as carefully as usual? RE

- Yes
- No

Q8. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)? Pain

- Slightly
- Moderately
- Quite a bit

These questions are about how you feel and how things have been with you during the past 4 weeks. For each question please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks....

Q9. Have you felt calm and peaceful? MH

- Most of the time
- Some of the time
- None of the time

Q10. Did you have a lot of energy? Vitality

- Most of the time
- Some of the time
- None of the time

Q11. Have you felt downhearted and blue? MH

- Most of the time
- Some of the time
- None of the time

Q12. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc.)? SF

- Most of the time
- Some of the time
- None of the time

**CHECK OF DATA**

Has the participant declined to answer any questions in this section	<input type="checkbox"/> yes	<input type="checkbox"/> no
If yes, please indicate which question they declines to answer and provide a reason. (eg Q4 – refused to answer; Q7 – even with prompting did not know how to answer).		

## Center for Epidemiologic Studies Depression Scale (CESD-R), NIMH

Below is a list of the ways you might have felt or behaved. Please tell me how often you have felt this way during the past week.

	During the past week			
	Rarely or none of the time (less than 1 day )	Some or a little of the time (1-2 days)	Occasionally or a moderate amount of time (3-4 days)	Most or all of the time (5-7 days)
Q1. I was bothered by things that usually don't bother me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q2. I did not feel like eating; my appetite was poor.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q3. I felt that I could not shake off the blues even with help from my family or friends.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q4. I felt I was just as good as other people.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q5. I had trouble keeping my mind on what I was doing.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q6. I felt depressed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q7. I felt that everything I did was an effort.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q8. I felt hopeful about the future.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q9. I thought my life had been a failure.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q10. I felt fearful.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q11. My sleep was restless.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q12. I was happy.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q13. I talked less than usual.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q14. I felt lonely.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q15. People were unfriendly.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q16. I enjoyed life.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q17. I had crying spells.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q18. I felt sad.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q19. I felt that people dislike me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q20. I could not get "going."	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**ANNEXIV:( Bengali)**  
**Questionnaire(প্রশ্নপত্র)**

মৃত্যুরনথি(শুধুমাত্রএকটিটিকিচিহ্নকরুন)

	হ্যাঁ	না
প্রঃ১ অংশগ্রহণকারী কি মারা গেছেন?	<input type="checkbox"/>	<input type="checkbox"/>
প্রঃ২ মারা যাওয়ার তারিখ:	____/____/____ দিনমাসবছর	
প্রঃ৩ মারা যাওয়ার তারিখ:	<input type="checkbox"/> সঠিক জানা আছে <input type="checkbox"/> সঠিক জানা নেই তবে ১ মাসের মধ্যে <input type="checkbox"/> সঠিক জানা নেই তবে ৩ মাসের মধ্যে <input type="checkbox"/> সঠিক জানা নেই তবে ৬ মাসের মধ্যে <input type="checkbox"/> সঠিক জানা নেই তবে ১ বছরের মধ্যে <input type="checkbox"/> সঠিক জানা নেই তবে ১ বছরের বেশি বললে ভুল বলা হবে।	
প্রঃ৪ মারা যাওয়ার কারণ:		
প্রঃ৫ আপনাকে কে বলছে যে অংশগ্রহণকারী মারা গেছে? শুধুমাত্র অংশগ্রহণকারীর সম্পর্কের বিবরণ প্রদান করুন (অংশগ্রহণকারীর মাতা-পিতা, অংশগ্রহণকারীর বন্ধু) এই পৃষ্ঠায় নাম প্রদান করবেন না।		
প্রঃ৬ পরিবারের সদস্য থেকেও অন্য কাউকে যদি আপনি বিশ্বাস করেন এটা আপনাকে বলার জন্য যে অংশগ্রহণকারী মারা গেছে – দ্বিতীয় একজন স্বাধীন চিন্তাশীল ব্যক্তি নিশ্চিত করেছেন যে ব্যক্তি মারা গেছে?	<input type="checkbox"/> হ্যাঁ <input type="checkbox"/> না	

<p>প্রঃ৭ উপরেযদিউত্তর হ্যাঁ আসে – দ্বিতীয়ব্যক্তিকে আপনাকেবলছেনযেঅংশগ্রহণকারীমারাগেছে? (উদাহরণস্বরূপঅংশগ্রহণকারীরঅভিভাবক, অংশগ্রহণকারীরবন্ধু). এইপূর্ণায়নামপ্রদানকরবেননা।</p>	
<p>প্রঃ৮ অংশগ্রহণকারীরমৃত্যুরবিষয়েপ্রদত্তকোনতথ্যথাকলে অনুগ্রহ করে প্রকাশকরুন:</p>	

## অংশগ্রহণকারীর অসনাত্তকারীবিবরণ

বৈবাহিকঅবস্থা:

(শুধুমাত্রএকটিটিকিচিহ্নকরুন)

প্রঃ ১ (ক). আপনারবর্তমানবৈবাহিকঅবস্থাকি: (শুধুমাত্রএকটিটিকিচিহ্নকরুন)	<input type="checkbox"/> বিবাহিত <input type="checkbox"/> অবিবাহিত <input type="checkbox"/> বিচ্ছিন্ন / ডিভোর্সড <input type="checkbox"/> বিধবাবাবিপল্লীক
প্রঃ ১ (খ). আপনারসন্তান কয়জন :	
প্রঃ ১ (গ). আপনার SCI হবার ৯ মাস পর কতজন সন্তানজন্মহয়:	

## অংশগ্রহণকারীশিক্ষা, সামাজিকএবংকর্মবিবরণ

এইপ্রশ্নগুলিঅংশগ্রহণকারীরবর্তমানপরিস্থিতিটিউল্লেখকরে

প্রঃ ২ (ক). কোথায়আপনিবর্তমানেবসবাসকরেন? (শুধুমাত্রএকটিটিকিচিহ্নকরুন)	<input type="checkbox"/> নিজেরবাড়িতে / পিতামাতাবাপরিবারেরসদস্যেরবাড়ি <input type="checkbox"/> ভাড়াবাড়ী <input type="checkbox"/> নিজেরসমতল / পিতামাতারবাপরিবারেরসদস্যেরক্ল্যাট <input type="checkbox"/> ক্ল্যাটভাড়াদেওয়া <input type="checkbox"/> বস্তি অন্যান্য (উল্লেখকরুন) _____ — ———
প্রঃ ২ (খ). যখনআপনিচলে গেয়েছিলেনতখনআপনিকিগ্রামবাশহরে বাসকরতেন?	<input type="checkbox"/> শহর - নামদিন _____ <input type="checkbox"/> গ্রাম- নামদিন _____



<p>প্রঃ ৩ (ক). আপনার আঘাত পর থেকে, আপনি কি আর কাজ করেছেন?</p> <p>প্রঃ ৩ (খ). যদি হ্যাঁ, আপনার অবস্থান / পেশা কি ছিল?</p>	<p><input type="checkbox"/> হ্যাঁ <input type="checkbox"/> না</p> <hr/>
<p>প্রঃ ৪. আপনার বর্তমান কাজের অবস্থা কি? (শুধুমাত্র একটি টিক চিহ্ন করুন)</p>	<p><input type="checkbox"/> পূর্ণ সময় নিযুক্ত (যেমন, কাজ &gt; প্রতি সপ্তাহে ৩০ ঘন্টা)</p> <p><input type="checkbox"/> আংশিক সময় নিযুক্ত (যেমন, &lt; ৩০ ঘন্টা প্রতি সপ্তাহে কাজ)</p> <p><input type="checkbox"/> অবসরপ্রাপ্ত</p> <p><input type="checkbox"/> বেকার</p> <p><input type="checkbox"/> ঘরের কাজ</p> <p><input type="checkbox"/> ছাত্র</p> <p><input type="checkbox"/> স্বৈচ্ছাসেবক</p> <p><input type="checkbox"/> উপরের কোনটিই নয় (দয়াকরে নির্দিষ্ট করুন)</p>
<p>প্রঃ ৫. প্রতি মাসে আপনার বর্তমান আয় (টাকায়) কি?</p>	<p>বিডিটি</p> <hr/>
<p>প্রঃ ৬. আপনি বর্তমানে আপনার পরিবারের প্রধান উপার্জনকারী কি?</p>	<p><input type="checkbox"/> হ্যাঁ <input type="checkbox"/> না</p>

<p>প্রঃ ৭. আপনার সাথে আপনার বাড়ীতে কতজন বর্তমানে বসবাস করছেন?</p>	<p>প্রাপ্ত বয়স্কদের সংখ্যা:</p> <p>সন্তান সংখ্যা:</p>
--	--

<p>প্রঃ ৮. আপনার পরিবারের অন্যান্য ব্যক্তিরা বর্তমানে কতজন বেতন ভোগী চাকরি করছেন?</p>	<p>বিডিটি</p> <hr/> <hr/>
<p>প্রঃ ৯. আপনার বাড়িতে প্রতি মাসে (টাকায়) বর্তমান মিলিত আয় কী? (এই পরিমাণ অংশগ্রহণকারী এর আয় অন্তর্ভুক্ত করা উচিত)।</p>	<p>বিডিটি</p> <hr/> <hr/>

প্রঃ ১০. এ। আপনার প্রধান যন্ত্রকারীকে / কারা : (যথাযথভাবে টিক চিহ্ন দিন)	টিক
স্ত্রী বা স্বামী	<input type="checkbox"/>
মামা বা বাবা	<input type="checkbox"/>
পিতামহ	<input type="checkbox"/>
কন্যা বা পুত্র বধু	<input type="checkbox"/>
পুত্র বা শশুর	<input type="checkbox"/>
বোন	<input type="checkbox"/>
ভাই	<input type="checkbox"/>
বেতনভুক্ত কর্মচারী	<input type="checkbox"/>
অন্যান্য (উল্লেখ করুন)	<input type="checkbox"/>
জানা নেই	<input type="checkbox"/>

### অন্যান্য বিস্তারিত

প্রঃ ১১. ২০১১ সালে এখান থেকে যাওয়ার পর-আপনার চলাচলের জন্য একটি হইল চেয়ার প্রয়োজন ছিল কি ?	<input type="checkbox"/> হ্যাঁ	<input type="checkbox"/> না
--	--------------------------------	-----------------------------

প্রঃ ১২. বর্তমানে - দৈনন্দিন আপনার চলাচলের জন্য একটি হইল চেয়ার প্রয়োজন?	<input type="checkbox"/> হ্যাঁ	<input type="checkbox"/> না
---	--------------------------------	-----------------------------

### তথ্য চেক

প্রঃ ১৩. অংশগ্রহণকারী এই বিভাগে কোন প্রশ্ন উত্তর দিতে প্রত্যাখ্যান করেছে	<input type="checkbox"/> হ্যাঁ	<input type="checkbox"/> না
প্রঃ ১৪. যদি হ্যাঁ হয়, তাহলে কোন প্রশ্নটি উত্তর দিতে অস্বীকার করে এবং কোন কারণ প্রদান করে তা নির্দেশ করুন। (উদাহরণ স্বরূপ প্রশ্নঃ ৪- উত্তর দিতে প্রত্যাখ্যান; প্রশ্ন ৭ - উত্তর দেওয়ার সাথে সাথে প্ররোচনা দেওয়া ও জানতনা)		

## WHODAS – v2 – Participation Items

### ক্ষেত্র ৬ অংশ গ্রহনঃ

এখন আমি আপনাকে জিজ্ঞেস করব সমাজে আপনার অংশগ্রহন এবং আপনার নিজের ও পরিবারের উপর আপ-  
শারীরিক সমস্যার প্রভাব সম্পর্কে। কিছু প্রশ্ন হতে পারে বিগত ৩০ দিন আপের আপনার সমস্যা সম্পর্কে উত্তর দে  
সময় অনুগ্রহপূর্বক বিগত ৩০ দিনের উপর আলোকপাত করবেন। আরো আমি আপনাকে মনে করিয়ে দিতে চা  
এই প্রশ্নগুলোর উত্তরের সময় শারীরিক, মানসিক বা আবেগীয়, মদ্যপান বা মাদক জনিত সমস্যার কথা বলবেন

ফ্লাশকার্ড ০১ এবং ফ্লাশকার্ড ০২ দেখিয়ে-

বিগত ৩০ দিনেঃ	কোন সমস্যা নাই	খুব অল্প সমস্যা	মাঝারি সমস্যা	তীব্র সমস্যা	প্রচন্ড বাঁ করা প
০৬.১ সামাজিক অনুষ্ঠান গুলোতে (যেমন উৎসব, ধর্মীয় অনুষ্ঠান বা অন্যান্য কর্মকাণ্ড) অন্যদের মত অংশ গ্রহন করতে গিয়ে কোন অসুবিধার মুখোমুখি হয়েছেন?	১	২	৩	৪	
০৬.২ আপনার পারিপার্শ্বিক বাধা-বিঘ্নের দরুন কতটুকু সমস্যায় পড়েছেন?	১	২	৩	৪	
০৬.৩ অন্যের দৃষ্টিভঙ্গি ও কাজের কারণে আপনি মর্যাদাপূর্ণ জীবনযাপনে কতটুকু সমস্যায় পড়েছেন?	১	২	৩	৪	
০৬.৪ আপনার শারীরিক সমস্যা ও এর ফলে উদ্ভূত সমস্যাগুলোর জন্য কতটুকু সময় ব্যয় করেন?	১	২	৩	৪	
০৬.৫ নিজের শারীরিক সমস্যার কারণে কতটুকু আবেগ তারিত হন?	১	২	৩	৪	
০৬.৬ আপনার শারীরিক সমস্যার কারণে আপনার বা পরিবারের কী পরিমান আর্থিক ক্ষতি হচ্ছে?	১	২	৩	৪	
০৬.৭ আপনার শারীরিক সমস্যার কারণে আপনার পরিবার কতটুকু ভুক্তভোগী ?	১	২	৩	৪	
০৬.৮ বিশ্রাম বা বিনোদনের জন্য কিছু করতে গিয়ে আপনি কতটুকু সমস্যায় পড়েছেন ?	১	২	৩	৪	

## এসএফ-12 স্বাস্থ্য জরিপ

নির্দেশনা: এই প্রশ্নডুবমালা আপনার স্বাস্থ্য সম্পর্কে আপনার মতামত জানার জন্য। এই তথ্য বুঝাতে সাহায্য করবে যে, আপনি কেমন বোধকরেন এবং আপনার স্বাভাবিক কাজকর্ম আপনি কতটা ভালভাবে করতে পারেন। নিম্নেডুবর প্রত্যেকটি প্রশ্নেডুবর জন্য একটি ঘরেটিক চিহ্ন দিবেন যেটা আপনার জন্য সবচেয়ে ভালউ উত্তর বোঝায়।

১. ১। সবমিলে আপনিবলবেন কি আপনার স্বাস্থ্য:

- চমৎকার
- খুব ভালো
- ভালো
- মোটামোটি
- খারাপ

নিম্নেডুবর প্রশ্নডুব গুলো, একটি স্বাভাবিক দিনে আপনি যেসবকর্মকা-করতে পারেন সে সম্পর্কে। আপনার স্বাস্থ্য কি বর্তমানে এসবকর্ম কা-ব্যাঘাত ঘটায়? যদি তাই হয়, তবে কতটা?

২. ২. মাঝারি কষ্টের কাজ যেমন একটা টেবিল সরানো, মাঝারি সাইজের পানি ভর্তি একটা বালতি সরানো

- হ্যাঁ, অনেকটা ব্যাঘাত ঘটায়
- হ্যাঁ, কিছুটা ব্যাঘাত ঘটায়
- না, কোনো ব্যাঘাত ঘটায় না

৩. ৩. কয়েক তলা সিঁড়ি ওঠা

- হ্যাঁ, অনেকটা ব্যাঘাত ঘটায়
- হ্যাঁ, কিছুটা ব্যাঘাত ঘটায়
- না, কোনো ব্যাঘাত ঘটায় না

শারীরিক কারণে গত ৪ সপ্তাহে আপনার কাজে বা অন্য স্বাভাবিক দৈনন্দিন কর্মকা-নিম্নেডুবর উল্লেখিত কোন সমস্যা হয়েছিল কি?

৪. ৪. যতটুকু চেয়েছিলেন তার চেয়ে কম সম্পন্নডুব করেছিলেন

- হ্যাঁ
- না

৫. ৫. দৈনন্দিন একই রকম কাজ বা কর্মকাণ্ডে-সীমাবদ্ধ ছিলেন

হ্যাঁ না

আবেগ জনিত সমস্যার (যেমনবিষনড়বতা বোধবা দুশ্চিন্তার) গত ৪ সপ্তাহে আপনার কাজে বা অন্য নিয়মিত দৈনন্দিন কর্মকাণ্ডে-নিশ্চেষ্টবর কোনো সমস্যা হয়েছিল কি?

৬. ৬.যতটুকু চেয়েছিলেন তার চেয়ে কম সম্পন্নড়ব করেছিলেন

হ্যাঁ না

৭. ৭.কাজ বা অন্য কর্মকাণ্ডে- যেমন যতড়ব সহকাণ্ডে করেন তেমন করতে পারেন নাই

হ্যাঁ না

৮. ৮. ব্যাথা গত ৪ সপ্তাহে আপনার স্বাভাবিক কাজকে (বাড়ীএবংবাড়ীরবাইরে) কি পরিমান ব্যাহত করেছিল?

- একে বারেইনা
- সামান্য
- মোটামোটি
- বেশকিছু
- চরম মাত্রায়

এই প্রশড়বগুলো গত ৪ সপ্তাহে কেমন বোধ করেছিলেন এবং অন্যান্য বিষয়গুলো কেমনছিল সেই সম্পর্কে। প্রত্যেক প্রশড়বের জন্য আপনি যেমন বোধ করেছিলেন তার সবচেয়ে কাছাকাছি একটি উত্তর দিবেন। গত ৪ সপ্তাহে কত টুকু সময়ের জন্য

৯. ৯. আপনি ধীরস্থির ও শান্তিপূর্ণ বোধ করেছিলেন?

- গবসময়
- প্রায়সময়
- বেশ কিছুসময়

- কিছু সময়
- সামান্য সময়
- কোন সময়ইনা

১০. ১০.। আপনার প্রচুর কর্মশক্তি ছিলো?

- গবসময়
- প্রায়সময়
- বেশ কিছুসময়
- কিছুসময়
- সামান্য সময়
- কোনসময়ইনা

১১. ১১.। আপনি মনমরা ও হতাশা বোধ করেছিলেন?

- গবসময়
- প্রায়সময়
- বেশকিছুসময়
- কিছুসময়
- সামান্য সময়
- কোনসময়ইনা

১২. ১২.। শারীরিক বা আবেগ জনিত সমস্যা গত ৪ সপ্তাহে আপনার সামাজিক কর্মকা- (যেমনবন্ধু ও আত্মীয়দের সাথে দেখাকরা) কতটা সময় ব্যাঘাত ঘটিয়েছিল?

- গবসময়
- প্রায়সময়
- বেশকিছুসময়
- কিছুসময়
- সামান্য সময়
- কোনসময়ইনা

## Center for Epidemiologic Studies Depression Scale (CESD-R), NIMH

গত এক সপ্তাহে কত সময় ধরে আপনি নিম্নে বর্ণিত ভাবে অনুভব বা আচরণ করেছেন?

	MZ GK সপ্তাহে			
	কদাচিত্বা কখনো না (১ দিনের কম)	কখনো কখনো (১-২ দিন)	মাঝে মাঝে (৩-৪ দিন)	অধিকাংশ গময় বা সব সময় (৫-৭ দিন)
১. ১. যে সব বিষয় আমাকে সাধারণত বিরক্ত করেনা সেগুলো দ্বারা আমি বিরক্ত হতাম	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
২. ২. আমার খাবারের রুচি কম ছিল	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
৩. ৩. মনেহত পরিবার বা বন্ধুদের সহায়তা রপরেও আমি আমার হতাশা ঝেড়ে ফেলতে পারবোনা	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
৪. ৪. মনেহতআমিঅন্য সবারমতভালোআছি	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
৫. ৫. আমার কাজে মনোযোগ দিতে সমস্যা হত	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
৬. ৬. আমার হতাশা অনুভূত হত	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
৭. ৭. মনে হত যাকরছি তা মনের বিরুদ্ধে বা জোর করে	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
৮. ৮. আমি ভবিষ্যৎ নিয়ে আশাবাদী ছিলাম	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
৯. ৯. মনে হত আমার জীবনটা ইবা	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

১০. ১০. আমার ভয় হত	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
১১. ১১. আমার ঠিকমত ঘুম হত না	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
১২. ১২. আমি সুখী ছিলাম	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
১৩. ১৩. আমি স্বাভাবিকের চেয়ে কম কথা বলতাম	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
১৪. ১৪. আমার নিজেকে একা বা নিঃসঙ্গ মনে হত	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
১৫. ১৫. লোকজনের কাছ থেকে বন্ধুসুলভ আচরণ পেতাম না	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
১৬. ১৬. আমি জীবনটা উপভোগ করতাম	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
১৭. ১৭. আমার কানড়বা পেত	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
১৮. ১৮. আমি দুঃখ পেতাম	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
১৯. ১৯. আমার মনে হত লোক জন আমাকে পছন্দ করেনা	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
২০. ২০. আমার জীবন যাপন দুর্বিসহ ছিল	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



## ANNEX VI: Approval letter



# বাংলাদেশ হেল্থ প্রফেশন্স ইনস্টিটিউট (বিএইচপিআই) Bangladesh Health Professions Institute (BHPI)

(The Academic Institute of CRP)

Ref.

CRP-BHPI/IRB/03/18/205

Date: 25/03/22

To  
Md. Akhlasur Rahman  
M.Sc in Rehabilitation Science  
Session: 2016-2017, Student ID: 181160048  
BHPI, CRP, Savar, Dhaka-1343, Bangladesh

**Subject: Approval of thesis proposal "Evaluation of the Spinal Cord Injury Patients at the end of Five Years after Discharge from CRP" by ethics committee.**

Dear Md. Akhlasur Rahman,

Congratulations!

The Institutional Review Board (IRB) of BHPI has reviewed and discussed your application to conduct the above mentioned dissertation with yourself, as the Principal investigator. The following documents have been reviewed and approved:

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

Since the study involves evaluation of the Spinal Cord Injury (SCI) patients at the end of five years following discharge after spinal cord injury from Centre for the Rehabilitation of the Paralyzed (CRP) and data will be collected from the CRP Savar and communities in Bangladesh through interviewer administered "SCI Secondary Condition Sale, Center for epidemiologic Studies Depression Scale, Quality of life:SF12, WHO Disability Assessment schedule Scale", that takes maximum 25 to 30 minutes and have no likelihood of any harm to the participants, the members of the ethics committee have approved the study to be conducted in the presented form at the meeting held at 9:00 AM on October 08, 2017 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

সিআরপি-চাপাইন, সাভার, ঢাকা-১৩৪৩, বাংলাদেশ, ফোন : ৭৭৪৫৪৬৪-৫, ৭৭৪১৪০৪ ফ্যাক্স : ৭৭৪৫০৬৯

CRP-Chapain, Savar, Dhaka-1343, Tel : 7745464-5, 7741404, Fax : 7745069, E-mail : contact@crp-bangladesh.org, www.crp-bangladesh.org