Evaluating Social Participation among the People with Spinal Cord Injury (SCI) in Dhaka District

By

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Dedicated to

My Beloved parents………

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WHO: World Health Organization

CRP: Centre for the Rehabilitation of the Paralyzed

SCI: Spinal Cord Injury

PLWSCI: Person Living With Spinal Cord Injury

ICF: International Classification of Functioning, Disability and Health

ABSTRACT

Background: People with spinal cord injury have faced many challenges in their community life after completing their rehabilitation. Some of them can engage in their social events in modifying way, but many of them can not engage in their social events properly. It also restricts their ability and quality of life.

Objective: This study identified the level of participation among people with spinal cord injury in the community of Dhaka district. The purpose of this study was to evaluate social/community participation among people living with spinal cord injury. The study also identified the socio-demographic information, injury related information, socio-economic information and health status of the participants. This study also showed the association between demographic informations (age, gender, occupation and assistive device) and social participation of the participants.

Methodology: The study was conducted through cross-sectional design in quantitative study among 70. Participants were selected by using purposive sampling process. Data were collected by conducting face to face interview and used the “Participation scale”. Chi-square test was used to find out the association between demographic information and social participation.

Result: In this study, as a evaluation of social participation of people living with SCI in their community, it was found that, about 28.6% (n=20) respondent’s are in “No significant restriction stage (score: 0-12)”, about 43.3% (n=31) respondent’s are in “Mild restriction stage (score: 13-22)”, and about 18.6% (n=13) respondent’s are in “Moderate restriction stage (score: 23-32)”. Besides, about 7.1% (n=5) respondent’s are in “Severe restriction stage (score: 32-52)” and about 1.4% (n=1) respondent’s are in “Extremely restriction stage (score: 53-90)”. In this study, about health status, it was found from total respondents (n=70) that, about 41.4% (n=29) respondent’s perception of health is fair, 32.9% (n=23) respondent’s perception of health is good and 12.9% (n=9) respondent’s health perception is very good. Besides, about 10.0% (n=7) respondent’s health perception is excellent and 2.9% (n=2) respondent’s health perception of health is poor.

Conclusion: The result of the study will be helpful to know about the level of participation among the people with spinal cord injury who living in their own community of Dhaka district. The result will also very helpful to know about the demographic and health status of the participants. It is very essential to address their participation restriction. This study provides the basis for identifying levels of social participation of community living spinal cord injured people at individual perspective which open the need for foundations for country level participation data to inform policy and set-up rehabilitation.

Key words: Participation, Social/community participation, Participation restriction, community, Environmental factors, Spinal cord injury, People living with spinal cord injury.

CHAPTER 01 INTRODUCTION

1.1 Background:

A spinal cord injury (SCI) is a devastating condition with results in enormouspersonal and psychosocial consequences.People living with SCI (PLWSCI) have to cope with various challenges, of which adapting to community life isone of the greatest. The main challenge for PLWSCI starts when they returnhome after institutionalized rehabilitation and they have to reintegrate into andparticipate in their communities again. Community participation requires beingable to fulfill their roles as members of their households, participants in theircommunities, and citizens of their world. Such participation in the community isthe ultimate outcome of rehabilitation for people with disabilities, includingspinal cord injury (University of Pretoria, 2010). This thesis evaluates social participation among people living with spinal cord injury (PLWSCI) in their own community of Dhaka district, Bangladesh.

Bangladesh is a developing country and most densely populated country situated at south Asia in the world. Bangladesh has a population of 152,518,015 which ranks Bangladesh 8th in the world, 27% of them live in urban areas and the majority (73%) live in rural areas (Bangladesh Bureau of Statistics, 2011). There are an estimated 16 million people with disabilities in Bangladesh, or 10% of the country's population (Centre for Disability in Development, 2016;&World Bank report,2016).The prevalence of disability was about 6% among those below the age of 18 and about 14% among those above that age (World Bank report, 2016). According to WHO disability report 2011, estimates of disability prevalence of Bangladesh from World Health Survey (2002-2004) is 31.9%. (WHO,2011). There are an estimated 16 million people with disabilities in

Bangladesh, or 10% of the country's population(Centre for Disability in Development, 2016; &World Bank report, 2016).

In 2004, the prevalence of disability was about 6% among those below the age of 18 and about 14% among those above that age(World Bank report, 2016).According to disability in Bangladesh, the total figure of disability is increasing with population growth and aging.The disease and injury which affect the spinal cord and damage the neurological level are the important health problem in our country, so they carry high rates of morbidity and mortality. Because, people with spinal cord injury faces lots of restriction in their daily activities and social participations (Hoque et al., 1999).

Besides, Social participation is a key indicator of successful aging and is associated with mortality,morbidity(Australian Health Review, 2017)and quality of life (Levasseur M. et al; 2010). Enhancing social participation is a central component of the World Health Organization’s response to concerns about population aging (WHO, 2011). People with SCI and their care giver cannot carry enough knowledge about SCI and faces main challenge in their own community life after completing rehabilitation. For that, SCI people faced different social problems like accessibility barriers, family burdens, economic crisis, sexual violation, livelihood and other livelihood challenges(Hoque et al., 1999). Besides, for lacking of proper knowledge, it is difficult for care giver to take care of SCI people in different secondary complications like pressure sore, muscle spasticity, muscle contracture, pain etc. Social stigma and prejudice creates negative effects on people with SCI about their social participation (Jorgensen S, Iwarsson S, Lexell J, 2016). In many cases, it is seen that, the survival rate is too poor in the community, for care-givers poor knowledge and interest of caring people with SCI. Career education is a very important aspect about that. In other sides, 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, 2011).

People who have been suffering from spinal cord injury often face life threatening complications so they need appropriate management and specialized rehabilitation. The patients of SCI are going into the different hospital for the treatment but they do not have enough facilities for their treatment. In Bangladesh there is only one non-government organization is Centre for the Rehabilitation of the Paralyzed, which has conducting a rehabilitation program for the last 32 years through which the patients can improve their life style (Islam et al., 2011). After completing rehabilitation from CRP, it is very important to know that, how the people with SCI lead their life in their community, how much satisfaction achieved by them and how much problems/difficulty, they faced in their life event. The nongovernmental special organization, CRP managed the patients with multi and inters disciplinary approach which emphasis on the development of community based 3 rehabilitation programs (Centre for the Rehabilitation of the Paralyzed. Annual report: 2014–2015).

There are sufficient stuffs that work there sincerely and supported by short term volunteers from home to abroad (Hoque et al., 1999). For developing effective program and polices the study will help to further enhancing our knowledge about SCI in Bangladesh.

In developing countries, advance care ICU and proper, accurate and long term management and rehabilitation have the survival rate and life expectancy which is available only in the non-government organization (Islam et al., 2011)

According to International Classification of functioning (ICF), Disability is an umbrella term for impairments, activity Limitations and participation restrictions. It denotes the negative aspects of the interaction (Environment and personal factors) (WHO, 2001).

According to ICF, Participation means Involvement in a life situation, activity is the execution of a task or action by an individual, and Participation restrictions are Problems an individual may experience in involvement in life situations.

Participation requires that individuals are entitled to participate in the decisions that directly affect them, including in the design, implementation, and monitoring of health interventions. In practice, meaningful participation may take on a number of different forms, including informing people with balanced, objective information, consulting the community to gain feedback from the affected population, involving or working directly with communities, collaborating by partnering with affected communities in each aspect of decision making including the development of alternatives and identification of solutions, and empowering communities to retain ultimate control over the key decisions that affect their wellbeing. (WHO, Human rights and Gender Equality in health sector strategies; 2008)

The International Classification of Functioning, Disability and Health (ICF), defines participation as "involvement in a life situation". Assessing someone's level of participation is seen as essential to understand the social impact of a disability on a person's life. (Martinuzzi, A, Salghetti, A, Betto, S, et al, 2010). Participation represents the social perspective of functioning. Participation restriction means problems in an individual may experience in involvement in life situations (ICF). Determined by comparing an individual's participation to that which is expected of an individual without disability in that culture society (Ustun et al., 2003).

Social participation is a crucial direction for policy to promote health equity concerns the participation of civil society and the empowerment of affected communities to become active protagonists in shaping their own health. Broad social participation in shaping policies to advance health equity is justified on ethical and human rights grounds, but also pragmatically. (WHO, 2008).

The Participation scale (p-scale) focuses on social/community participation and usually used to find out the level of participation and also participation restriction of people who are affected by disability. The p-scale is also use in an Occupational Therapy department in a hospital or rehabilitation centre (van Brakel et al, 2006). The Participation scale has been validated for use with people affected by leprosy, people with spinal cord injuries (SCI), polio and other disabilities. Extensive validation and field testing have confirmed that the scale works well under different operational circumstances (van Brakel et al, 2006).

Participation, believed to contribute to health and well-being for people with disabilities (Fredricks, JA, Eccles, JS. 2006). Participation or involvement in everyday occupations is vital for all humans. As described by the World Health Organization, participation has a positive influence on health and well-being for people with disabilities (like SCI). Several authors consider social participation as an indicator of health, well-being and positive social behaviours(Sørensen, LV, Waldorff, FB, Waldemar, G. 2008).

Social participation is also meaningful participations for the people with SCI in their own community, because, social participation helps the people with SCI to find out the actual own identity in the community and social participation is regarded as a key determinant of successful and healthy aging (Levasseur M et al., 2010).

In otherside, the term social participation is an area of occupation, encompasses and broadens the definition of social integration; it includes expected interactions with others in community, family and peer/friend social systems. After cmpleting rehabilitation, people with SCI are tried to apply all gathered techniques to lead a better life in their own community. If these can be tried successfully, so that, social participation is enhancing health and well-being for the people with SCI (American Occupational Therapy Association, 2002).

Major components of social participation are: home and family roles and activities, other productive roles (work, school and volunteering), social networks, leisure activities, mobility and economic self-sufficiency. (Dijkers M., 1998). Every components of social participation are meaningful and also very important for people with SCI to lead their life in community and that’s why, social participation is meaningful occupation for SCI (Dijkers M.,1998).

In terms of social participation, the social consequences of SCI produce changes in an idividual’s social roles and interactions, reesulting in need in several areas. (Dijkers M. Abela NB, Gans BM and Gordon W. 1995). In a study examinning the unmet needs of people with SCI (in different countries and nations) living in the community, a high or very high need relating to employment was reported by 22% of the sample (Cox RJ, amsters DI and Pershouse KJ, 2001).

In another study by Johnson et al, financial limitations were reported by 25% of their sample and comprised the largest category of nonmedical secondary complication (Johnson RL, 1998). Sapountzi-Krepia, Soumalis and papadakis found that, 82% of a sample of paraplegics living in Athens stated that they had atleast one UTI during their stay at home following discharge (Sapountzi-Krepia D et al 1998).

Chronic pain has also been found to be prevalent in people with SCI who live in community, with 82% of people reporting persistent, bothersome pain at some time alter discharge, many with pain that frequently interferes with daily living (Turner JA, Cardenas DD Warms CA, McClellan CB, 2001)

Finally, Occupational therapy focuses social participation of the people with SCI in their community life, to ensure their well-being and participation in ADLs as much as possible (St. Catherine University Online OTA, 17 April, 2017). The purpose of this study is to find out the level of participation among people with spinal cord injury in the community of Dhaka district.

1.2 Justification:

Participation in everyday occupations as much as possible is an important issue of individual people with SCI. Participation is a concept in the International Classification of Functioning, Disability and Health (ICF), defined as “involvement in a life situation”.

The goals of occupational therapy for SCI patient’s are to achieve maximum physical improvement, reduce deformities and facilitation of maximal independence in self-maintenance. Therapists educate the people with SCI about how to regain lost performance and compensatory technique. The main focus of occupational therapy treatment is to regain of self-care, productivity and leisure activities. Occupational therapist also educates and shares information about patient’s condition to family and caregivers.The result of this study will be helpful for occupational therapiststo prepare appropriate treatment plan and provide better intervention.

Caregiver is very important for people with SCI. Manypeople with SCI are dependent on their caregiver to perform activity. The caregiver is primarily involved in helping the people with SCI to live independently at home. Bangladeshi caregivers are not well known about post SCI community participation.

They also not have clear idea about the importance of participation. This study will be beneficial for client and caregiver. This study will help to create more awareness among patients and caregivers about the importance of active participation in community life.

This study is important to know about the level of participation among people with spinal cord injury in the community as it will provide the basis for indentifying kinds the levels of disability of community living spinal cord injured people at individual perspective which open the need of the foundations of the society experienced by the victims that expose to spinal cord injury.

This study will be beneficial for the Occupational Therapy department and occupational therapists, because many occupational therapists are already working in different settings (SCI, CBR) and work about SCI.This study will help them to increase the knowledge about the level of community/social participation of people with SCI.

There are some studies about activity limitation and participation restriction among SCI people. But this study mainly focuses social participation of people with spinal cord injury in their community. It is very much important to know that, how people with SCI lead their social life, how much difficulties/challenges are faced by them.

This study will evaluate the social participation of them; and their level of participation, health status would be known from this study, which is very important for health professionals. Besides, this study will helpful to find out the association between socio-demographic and socio-economic factors.

Researcher feels very much interest in this area as a student of occupational therapy. It is hoped that further resource will be developed in this area after completing this study. And in future when anyone wants to do future research in this area, health professionals can get ideas and valuable information’s from this study that will help them. The analysis of socio-demographic information’s, socio-economic information’s, health status information’s and participation scale information’s will provide significant evaluation of social participation among the people with spinal cord injury in Dhaka district.

1.3 Research question:

What is the level of participation among the people with spinal cord injury patient in the community of Dhaka district?

1.4 Aim and Objectives of the study:

- **Aim and General objective**

The aim and general objective of this study is to measure the level of participation among the people with spinal cord injury in the community of Dhaka district

- **Specific objectives**

1. To find out the level of social participation among people with spinal cord injury in the community of Dhaka district
2. To find out the association between socio-demographic factors and social participation

1.5 Operational definition:

Participation: A person's involvement in a life satiation. It represents the societal perspective of functioning. (Ustun et al,2010).

Community: A group of people living in the same place or having a particular characteristic in common.A community is a small or large social unit (a group of living things) that has something in common, such as norms, religion, values, or identity. Communities often share a sense of place that is situated in a given geographical area (e.g. a country, village, town, or neighborhood) or in virtual space through communication platforms.(James, Paul; Nadarajah, Yaso; Haive, Karen; Stead, Victoria (2012)

Functioning: It is an umbrella term for body functions, body structures, activities and participation. It denotes the positive aspects of the interaction between an individual (With a health condition) and that individual's environment and personal context. (Ustun et al., 2010).

Environments Factors: Contextual factors that include the background of a person's life and living, composed of components of the natural environment (Weather or terrain);the human-made environment (tools , furnishing, the built environment); social attitudes, customs, rules, practices and institutions, and other individuals.(Ustun et al,. 2010).

Spinal cord Injury:A spinal cord injury (SCI) is a medically complex and life-disrupting condition which leads to a wide range of func-tional impairments and health-related problems (Kirchberger I et al. 2010). It isknown that people with SCI experience difficulties withactivities of daily living (ADL) and taking part in socialactivities compared to those without a SCI (Kemp B, Adkins R, Thompson L. 2004; Thompson L, Yakura J, 2001; Barclay L, McDonald R, Lentin P.,2015). People living with a SCI in less resourced countries such as Bangladesh, face challenges due to limited access to health care,rehabilitation programs, and quality assistive devices (WHO 2013; Hossain MS et al., 2015).

People Living With Spinal Cord Injury (PLWSCI): For the purposes of this study, the abbreviation PLWSCI is used to refer to a person or peopleliving with spinal cord injury (paraplegic or quadriplegic andcomplete or incomplete), who were once patient with spinal cord injury atrehabilitation units of public and/or private hospitals, and have since beendischarged to their various homes/socio-economic environments. In instanceswhere reference is made to PLWSCI still in hospital or a rehabilitationinstitution, the term patientis used. The noun patient refers to an individualwaiting for or under medical treatment (Harris, 2007).

Social participation: Social participation as used in this study combines two terms, namely community integration and participation. Community integration refers to being part of the mainstream of family and community life, resuming normal roles andresponsibilities as appropriate to the PLWSCI’s age, gender and culture and being an active and contributing member of society (Dijkers, 1998). Participation is defined as involvement in everyday life situations (WHO, 2001). Community/social participation therefore requires that PLWSCI should overcome the many barriers imposed by their disability and the surrounding environment.

Participation restriction: Participation restriction means problems in an individual may experience in involvement in life situations. Determined by comparing an individual’s participation to that which is expected of an individual without disability in that culture society (Ustun et al., 2010)

CHAPTER 02 LITERATURE REVIEW

2.1 Spinal Cord Injury

A spinal cord injury (SCI) is a medically complex and life-disrupting condition which leads to a wide range of functional impairments and health-related problems(Kirchberger I et al. 2010). SCI, the common type of injury, is also a severely disabling condition and leads to a range of impairments and secondary health conditions. Patients with SCI experience difficulty participation in society in contexts such as work and leisure activities (Magasi et al., 2008).

Spinal cord injury (SCI) is a serious condition that results in loss of motor, sensory and autonomic function below the lesion level (de Groot et al., 2010). It isknown that people with SCI experience difficulties withactivities of daily living (ADL) and taking part in socialactivities compared to those without a SCI (Barclay L, McDonald R, Lentin P.,2015). People living with a SCI in less resourced countries such as Bangladesh, face challenges due to limited access to health care,rehabilitation programs, and quality assistive devices (WHO 2013; Hossain MS, Rahman MA, Bowden JL, Quadir MM, Herbert RD & Harvey LA; 2015).Spinal cord injury becomes a major cause of mortality, morbidity and continues to be one of the foremost causes of disability.

According to the estimation of 2011, there are 17 million people in the world experienced SCI in their life (NSCISC 2014). Every year, around the world, between 250000 and 500000 suffer a spinal cord injury (SCI). In the article of WHO (2013), it was claimed that, there is no reliable estimate of global prevalence. But estimated annual global incidence is 40 to 80 cases per million population. Spinal cord injury is a traumatic harm to the spinal cord that can result in alternation of normal motor, sensory and anatomic function (DeLisa, et al., 2005).

2.2 SCI feature

About the feature of spinal cord injury, there are found some types such as traumatic spinal cord injury, non-traumatic spinal cord injury. In these, some patterns are also included such as paraplegia, tetraplegia, complete SCI; incomplete SCI.

Traumatic spinal cord injury is harm to the spinal cord that can result in alternation of normal motor, sensory and anatomic function. Paraplegia and tetraplegia are the two common terms used in spinal cord injury. The central nervous system- CNS consists of the brain and spinal cord. The principle roles of the CNS are to integrate and co-ordinate incoming and outgoing neural signals and to carry out higher mental function, such as thinking and learning.Spinal cord is an extension of the brain, a thick bundle of nerve fibers from which individual nerve branches off to connect your brain with your muscles, skin and internal organs. The spinal cord carries message from the brain to the different parts of the body and also from the different parts of the body to the brain (DeLisa, et al., 2005).

Paraplegia involves the lower extremities. Paraplegia is an impairment in motor or sensory function of the lower extremities. It is usually caused by spinal cord injury or a congenital condition that affects the neural (brain) elements of the spinal canal. The area of the spinal canal that is affected in paraplegia is either the thoracic, lumbar, or sacral regions. If four limbs are affected by paralysis, tetraplegia or quadriplegia is the correct term. If only one limb is affected, the correct term is monoplegia.Spastic paraplegia is a form of paraplegia defined by spasticity of the affected muscles, rather than flaccid paralysis(American Spinal Injury Association & ISCOS, 2011).The American Spinal Injury Association classifies spinal cord injury severity. ASIA A being the complete loss of sensory function and motor skills below the injury. ASIA B is having some sensory function below the injury, but no motor function. ASIA C some motor function below level of injury, but half the muscles cannot move against gravity. ASIA D, more than half of the muscles below the level of injury can move against gravity. ASIA E which is the restoration of all neurologic function (American Spinal Injury Association & ISCOS, 2011).

Tetraplegia involves all extremities. Tetraplegia, also known as quadriplegia, is paralysis caused by illness or injury that results in the partial or total loss of use of all four limbs and torso; paraplegia is similar but does not affect the arms. The loss is usually sensory and motor, which means that both sensation and control are lost. Tetraparesis or quadriparesis, on the other hand, means muscle weakness affecting all four limbs. It may be flaccid or spastic. (Coulet, B.; Allieu, Y.; et al.2002; and Reinholdt, C. 2008).

2.3 The challenges for people living with SCI

Bangladesh is a 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 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 service. It is not surprisingly happened that they frequently develop life threatening complications (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 cord injuries in Bangladesh. People having spinal injury can go to any hospital of their choice for management, SCI is more prone to rural arearather thyan 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 hospitalSevere disability alters the individual's social and occupational role and position. People faced many barriers to participate in social life and limiting it, especially in the early period of his illness (Hossain et al. 2018)

SCI presents a number of challenges, barriers to the injured person, the rehabilitation team, the family and society at large. For a person who has sustained PLWSCI and who has sustained a complete high lesion (i.e. cervical), the challenge becomes even greater because this person loses functioning of all four limbs; hence the extent of “disability” becomes greater.

The challenge for the rehabilitation team in the case of a person with such a high lesion relates to prolonged rehabilitation periods and the management of health complications.It is even worse when the person is from an economically disadvantaged area, where the physical surroundings may not be suitable for wheelchairs, and where members of the community regard “crippled people” as cursed (Rouland & Lyons, 1989).

This might appear to be easier than return to work, but in practice encounters many difficulties. Belonging to informal groups is not an absolute necessity, but it must by desired by the people with SCI, who must make a fresh start from a lower or different position than before his illness. The fear of appearing helpless generates stress and neurosis. The new situation raises the fear of not being accepted by the group (Freeman, H. E., Levine, S., Reeder, L. G., 2007).For spinal cord injury, people faced a lot of personal, social and occupational challenges and barriers. So that, it can be told that, as a result of spinal cord injury, person will have various difficulties in social participation.

2.4 Social participation

Social participation is the extent of people's involvement and interaction with others in their local communities, neighbourhood and wider society. Many factors can influence social participation, including the facilities and resources available in the community or neighbourhood and the ease by which people can access them. Lancashire County Council's Community Projects team works with Lancashire residents to support projects to strengthen communities and improve health and wellbeing. (Lancashire, 2018)

Social participation can take on a number of different forms including:

- Informing people with balanced, objective information;
- Consulting whereby the affected community provides feedback;
- Involving or working directly with communities;
- Collaborating by parenting with affected communities in each aspect of the decision including the development of alternatives identification of solutions; and
- Empowering and ensuring that communities retain ultimate control over the key decisions that affect their well-being. (WHO, 2011; The world health report, 2008)

Social participation is a very important aspect for people living with spinal cord injury. Home and family roles and activities, other productive roles such as work, school, volunteering etc, social networks, leisure activities, social networks and economic self-sufficiency are the major components for SCI people (Dijkers M, 1998). Measuring people’s level of social participation can therefore be used to identify community needs.

In social participation, there are 3 most disrupted life habits in relation to the consequences of spinal cord injury (SCI): residence maintenance, participation in occupational (family roles, domestic tasks, employment) and recreational (attending cultural events, sports, fitness, games) activities. The least disrupted life habits were identified as verbal communicating skills, making friends and maintaining an emotional relationship with family. They concluded that, the quality of an individual's environment (eg. Climate, accessibility, labor market, social support) and level of injury appear to significantly influence their ability to maintain their life habits.

Greater life satisfaction has been documented when people with SCI were involved in productive activities such as work, leisure and education (Cushman L, Scherer MA, 2009) and is associated with community reintegration (Fuheer MJ, Potter C et al, 1992; Nosek MA, Fuheer MJ et al, 1995). In general, persons with SCI were satisfied with their lives but when reduced quality of life was identified it was particularly related to unsatisfactory work and leisure situations. (Schonherr MC, Groothoff JW et al, 2005)

Activity and participation are important but conceptually complex constructs, and this could well account for inadequacies in empirical research. Conceptual and methodological issues with the construct of participation and environmental factors interact with impairment (Whiteneck et. al., 2009). Participation is a highly valuable fact for people with SCI, their caregivers and society at large, because it is related to a person's ability to be an active and contributing member of society (Whiteneck, 2006). Participation is also important for disability and rehabilitation policy, and is the hallmark of legislative initiatives (Mbeki, 1997), the American with Disabilities Act of 1990 and the United Nations Standard for the Equalisation of Opportunities for PWD (WHO, 2001).

Participation requires that individuals are entitled to participate in the decisions that directly affect them, including in the design, implementation, and monitoring of health interventions. (WHO, Human rights and Gender Equality in health sector strategies).Participation, defined as social involvement in a life situation (WHO, 2001), is described as a central goal of rehabilitation when the International Classification of Functioning, Disability and Health (ICF) is used as a conceptual framework for rehabilitation (Cardol M, et al., 2002)

In terms of social participation, the social consequences of SCI produce changes in an idividual's social roles and interactions, reesulting in need in several areas. (Dijkers M. Abela NB, Gans BM and Gordon W. 1995). In a study examinning the unmet needs of people with SCI (in different countries and nations) living in the community, a high or very high need relating to employment was reported by 22% of the sample (Cox RJ, amsters DI and Pershouse KJ, 2001).

Results from such studies vary due to many factors, for example the characteristics of the sample and the definition of the employment used. However re-employment rates have been reported as ranging from 14 to 44 (Krause JS, 2003).

Therefore on the whole, work can be concluded to still be an elusive goal for many (Dijkers M, 1995), highlighting the need for the vocational rehabilitation and careers support to help individuals return to work (DeVivo MJ, 1992)

In another study by Johnson et al, financial limitations were reported by 25% of their sample and comprised the largest category of nonmedical secondary complication (Johnson RL, 1998). Sapountzi-Krepia, Soumalis And papadakis found that, 82% of a sample of paraplegics living in Athens stated that they had at least one UTI during their stay at home following discharge (Sapountzi-Krepia D et al 1998). Chronic pain has also been found to be prevalent in people with SCI who live in community, with 82% of people reporting persistent, bothersome pain at some time alter discharge, many with pain that frequently interferes with daily living (Turner JA, Cardenas DD Warms CA, McClellan CB, 2001). Social participation can be measured and evaluate by participation scale (18 points scale)

The Participation scale (P- scale) has 18 items, in which the person is asked to respond whether they perceived their level of participation as equal to their peer in each of the situations described by the scale items.

If the person considers that his or her level of participation is lower than that of his/her peer, representing a possible restriction to participation, he/she is also asked to indicate to what degree this is a problem in his/her daily routine (van Brakel, 2010)

The P-Scale aims to quantify the restrictions perceived by the individual in eight of the nine major areas of life defined by the ICF: learning and applying knowledge; communication; personal care; mobility; domestic life; interpersonal interactions and relationships; major areas of life; and community, social and civic life(van Brakel et al 2006).

An innovative characteristic of the scale is that the individuals are asked to compare themselves with a real or hypothetical“peer”– that is, someone who is similar to them in all respects, except for illness or disability.

This comparison was proposed to allow the representation of the roles and expectations for participation in different social and cultural contexts (van Brakel et al 2010). These special features indicate that the P-scale might be useful to assess client’s participation restrictions in diverse life situations. The p-scale is designed to assess and evaluate the participation of individuals with a health condition or disability (like SCI), especially conditions associated with stigmaand discrimination (van Brakel WH et al,2006)

Participation and environmental factors that interact with impairment are inadequately conceptualized in the ICF and that lack of theoretical clarity impedes successful measurement. Whereas the ICF suggests multiple methods for classifying activity and participation, participation and activity should be conceptualized and measured as distinct constructs. There are a number of conceptual distinctions between activity and participation. Activity is considered action by an individual that can be assessed as a characteristic of a person. Participation may involve numerous activities that occur with or for others to fulfill societal roles(Whitenecket al., 2009).

Participation is assessed at the level of person and environment. “Activity” was understood to refer to the broad class behavioral, cognitive, and emotional experiences of individuals. “Participation” by contrast, is considered to refer to persons interactions with their social environment. The drawing of this conceptual distinction between activity and participation is considered one option for utilization of ICF classifications and is consistent with other expressed theoretical positions (Whitenecket al., 2009).

The term community-based participation refers to “the extent of participation in religious, social, recreational, vocational, political and other organizational community groups and activities”. Community participation is essential to gain some insight after SCI. This will help to provide an indication of the effectiveness of post SCI interventions in the community and identify areas which need community strengthening.

Community participation develops the managerial and organizational capacity to increase control over the decision of one individual life so it is very important for post stroke survivor after rehabilitation. (Botha, UA, Koen, L, Joska, JA, Hering, LM and Oosthuizen, 2010).Social participation is vary in the situation of different county perspective, culture perspective and there are different results may be found from developed country perspective and developing/poor country perspective about social participation.

2.5 Own country perspective:

People living with a SCI in less resourced countries such as Bangladesh, face challenges due to limited access to health care,rehabilitation programs, and quality-assistive devices (World Health Organization. 2013; Hossain MS, 2015). In addition, they are vulnerable to life threatening complications such as pressure ulcers and urinary tract infectionsafter being discharged from a hospital; consequently, manyof them die within a few years of the SCI (WHO, 2013). More specifically, a recent study from Bangladesh reported that 19%of people who sustained a SCI were wheelchair-dependentand die within 2 years of discharge from hospital (Hossain MS et.al, 2015).There are scarce data on socio-demographic and injury-related factors contributing to activity limitations and participation restrictions in people with SCI in less-resourcedcountries. Previous studies, predominantly from affluentcountries, have examined that various factors such asincreasing age, time since the injury (Whiteneck G, Meade MA, Dijkers M, Tate DG, Bushnik T.,Forchheimer MB. 2004)female gender(Whiteneck G, 1999; Krause JS, Broderick L. 2004), and tetraplegia (Jorgensen S, Iwarsson S, Lexell J. 2016)were found to be associated with activity limitations and participation restrictionsin people with SCI. However, it is difficult to generalizethesefindings to less resourced regions/countries due to socio demographic and other contextual differences, suchas cultural beliefs, ethnic compositions, and politicalrepresentation. Previous studies have demonstrated anassociation between socio-demographic and injury relatedcharacteristics of people with SCI in Bangladesh (Hossain et tal. 2015;Islam MS, Hafez MA & Akter M. 2011).

For example, a study of 107 patients at the Centre for theRehabilitation of the Paralyzed (CRP) in 2011 identifiedthat most SCIs (93%) were caused by traumatic incidentssuch asroad traffic accident,fall from a height, impact of a heavy object onto the neckand/or back(Islam MS, Hafez MA, Akter M. 2011). Seventypercent of the study participants were less than 40 years old,83% of injured people were males, 65% were married,and 92% were residents in rural areas. In terms of thecharacteristics of SCI, tetraplegia and paraplegia accountedfor 46% and 54% of the injuries, respectively (Islam MS, Hafez MA, Akter M. 2011).

Another study reported that following SCI, the majorityof people were unemployed, house bound, and living inpoverty (Hossain MS, et al, 2015)

Besides, in the other part of south-east asia, in rural area of Nepal and India, many patients live in remote villages where subsistencefarming is the primary source of income, and where steep terrain,limited road access and inaccessible housing are often barriers to thoseusing mobility devices(Singh R, Sharma SC, Mittal R, Sharma A2003; Richardson SA. 1983;Goudel C. 2004).Without good community reintegration, patients are more likely toget secondary health complications, such as pressure ulcers (PU) andurinary tract infections (UTI), resulting in re-hospitalization or evendeath.(Prabhaka MM, Thakker TH, 1983; Goudel C. 2004; Herm FB, Spackman J, Anderson, 2000)

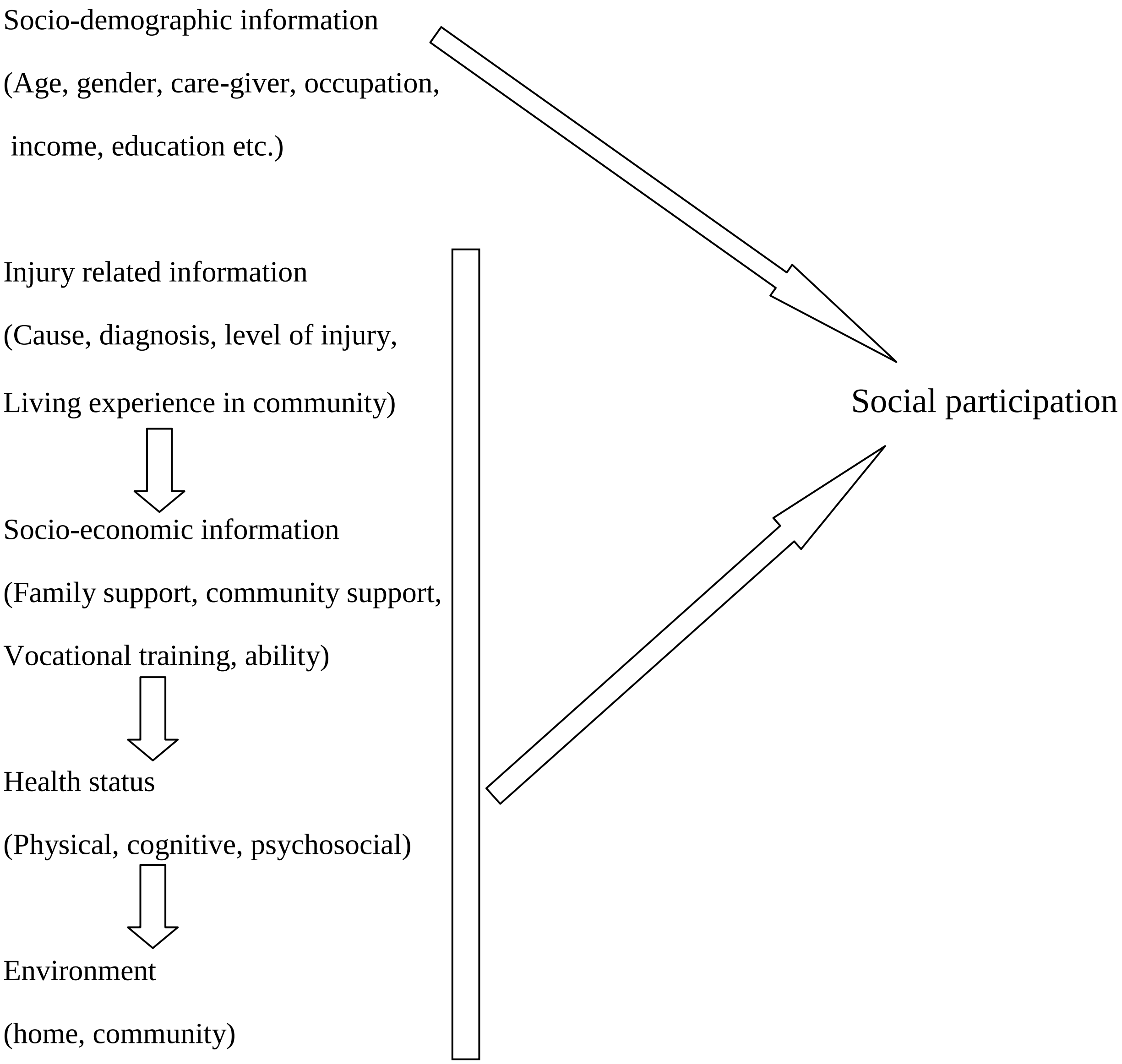
Secondary health complications are more common in Nepal in person with spinal cord injury. Besides, lack of home and work place accessibility are also more common issue in Nepal in person with SCI. In Nepal, Social participation rate for people with spinal cord injury is not in satisfactory level at all(hrestha D, Garg M, Singh GK, Singh MP, Sharma UK. 2007; Lakhey S, Jha N, Shrestha BP, 2005)

In conclusion, it can be said that, social participation might be well or in satisfactory level in developed country, because of their high income rate, good environment and accessibility facilities. These sides or facilities are not well or not in satisfactory level in low economic country, that’s why social participation might not be well in low-economic country.

CHAPTER 03 METHODOLOGY

3.1 Conceptual framework:

Dependent variableIndependent variable



Socio-demographic information

(Age, gender, care-giver, occupation,

income, education etc.)

Injury related information

(Cause, diagnosis, level of injury,

Living experience in community)

Socio-economic information

(Family support, community support,

Vocational training, ability)

Health status

(Physical, cognitive, psychosocial)

Environment

(home, community)

Social participation

3.2 Study design:

Descriptive cross sectional survey design was chosen to meet the study aim as an effective way to collect data. Descriptive cross sectional study is one of the forms of observational study. It is one of the most commonly used survey research design. It is an easy way to collect information among the large number of population in a short time. For this reason, researcher used this method for this study.

In this study, researcher used quantitative research design. A quantitative method is an appropriate method to know the subject well-known, comparatively simple and clear.Quantitative method is an easy way to collect information among large participant. The study was conducted by non-experimental cross-sectional survey research design. Researcher used this method to fulfill the aim and objectives of the study.

The researcher also chosen chi square test for this study. It is a statistical method assessing the goodness of fit between a set of observed values and those expected theoretically.

3.3 Study population:

Study population was people with spinal cord injury in their own community of Dhaka district.

3.4 Study setting:

Living area of people with spinal cord injury in Dhaka district. Researcher reached 13 places of Dhaka district in total (Mirpur, Dhanmondi, Lalbag, Shutrapur, Kotoali, Savar, Ashulia, Dhamrai, Dohar, Nouabgonj, Gabtoli, Katabon, Farmgate etc.).

3.5 Study period:

The period of this study was from September 2018 to February 2019

3.6 Sample size:

For calculating Sample size: the investigator used the principle of sample size determination:

$n = z^2.pq/r^2$ (Hicks, 2000). Sample size was estimated for this study according to the following formula- 95% confidence interval and 5% sampling error.

Here, the confidence interval is (z) = 1.96 and the sampling error (r) = 0.05 precise number of person with spinal cord injury was unknown as well as prevalence of was assumed p=0.5, where q= 0.5 (1-p) and then the sample size (n) it was stand for:

$$n = \frac{(1.96)^2 \times 0.5 \times 0.5}{(0.05)^2}$$

$$= 0.9604/0.0025$$

$$= 384.16$$

The calculated sample size is 384. But it is an educational research for the researcher and there were some limitations for the research work, like time limitation, cost limitation etc. That’s why, the researcher had collected data from 70 participant’s.

3.7 Inclusion criteria:

- Spinal cord injury patients (both of traumatic and non-traumatic) who completed rehabilitation from CRP and living in their own community after completing rehabilitation.
- Community living experience: Minimum 6 months and maximum 5 years
- Age: At least 18 years old.
- Both male and female
- Both paraplegic and tetraplegic SCI patient

3.8Exclusion criteria:

- Mentally unstable
- unwilling people
- Physically ill (like having of typhoid, jaundice, Pneumonia, severe fever etc.)
- Person with SCI below 18 years of age
- People with SCI who live in their own community for over 5 years

3.9 Sampling technique:

Researcher selected purposive sampling techniques to collect data and Purposive sampling starts with a purpose in mind and the sample is thus selected to include people of interest and exclude those who do not suit the purpose. Usually, the population is too large for the research to attempt to survey all of its members.

Researcher founded over ninety participant’s information from CBR department, CRP for data collection purpose. But, because of deathness and changing address, researcher reached 70 participants.

Purposive sampling technique were selected because it involves the deliberate selection of individuals by the researcher based on pre-define criteria and getting of those samples whose criteria was concerned with the study purpose. Here another factor is resource limitation to get the sample in bigger aspect as well as the limitation of time. Moreover, purposive sampling is a non-representive subset of some larger population, and is constructed to serve a very specific need or purpose (Oliver, 2013).

A small, but carefully chosen sample can be used to represent the population. The sample reflects the characteristics of the population from which it is drawn.As well as purposefully selected 70 people with SCI, who are living in their own community after completing rehabilitation from CRP.

3.10 Data collection tool:

Participation scale (P-scale) was the data collection tool. Other instruments are:

1. Information sheet

2. Consent form

3. Pen, Pencil

4. Eraser

5. Sharper

6. Consent from Participation scale (P-scale) 18 items Bengali version questionnaire.

3.10.1 Information sheet

Information sheet is an important for the participants that make sure the participant to participate the research.An information sheet is necessary to inform the participant about identity of researcher, institute affiliation, research related information such as title, aim, period, duties and privileges of participants. To provide information about researcher and subjects, researcher developed an information sheet in Bangla and English. Researcher was make sure about maintain confidentiality about their identity in this study by the information sheet. Data not shared to other person except research supervisor who was coordinating this study. The information sheet included that the participation was voluntary and this study was not any harm for the participant.

3.10.2Consent form

Consent form is an essential part where the person consents to do something. A consent form is necessary for a study and it is a standard way to get clearance or agreement of participation legally which is important before initial the collect data of any kind of research. To take consent from subjects, researcher developed a consent form in Bangla and English. Researcher was set printed consent form for participants to confirm the level of accepting of the information sheet, awareness about the potential benefits and risks as participant of thestudy. Researcher was taken permission from every single participant with signature on a written consent form. Volunteer participation of participants was permitted by signing.

3.10.3Participation scale

The Participation scale (p-scale) focuses on social/community participation and usually used to find out the level of participation and also participation restriction of people who are affected by disability. The p-scale is also use in an Occupational Therapy department in a hospital or rehabilitation centre (van Brakel, 2010). The Participation scale has been validated for use with people affected by leprosy, people with spinal cord injuries (SCI), polio and other disabilities. Extensive validation and field testing have confirmed that the scale works well under different operational circumstances (Van Brakel, 2010).

The Participation scale (P- scale) has 18 items, in which the person is asked to respond whether they perceived their level of participation as equal to their peer in each of the situations described by the scale items. If the person considers that his or her level of participation is lower than that of his/her peer, representing a possible restriction to participation, he/she is also asked to indicate to what degree this is a problem in his/her daily routine (van Brakel, 2010).

The individual's score on each item can be "No problem"=1, "Small"=2, "Medium"=3, "Large"=5. If the individual does not consider his/her participation less than that of his/her peer. To obtain the total score, values attributed to each items are added. The P- scale total score varies between 0 (zero) and 90, where 0= "no restriction on participation" and 90= "complete restriction in participation".

The P-Scale aims to quantify the restrictions perceived by the individual in eight of the nine major areas of life defined by the ICF: learning and applying knowledge; communication; personal care; mobility; domestic life; interpersonal interactions and relationships; major areas of life; and community, social and civic life(van Brakel et al 2006). An innovative characteristic of the scale is that the individuals are asked to compare themselves with a real or hypothetical"peer"– that is, someone who is similar to them in all respects, except for illness or disability. This comparison was proposed to allow the representation of the roles and expectations for participation in different social and cultural contexts (van Brakel et al 2006). These special features indicate that the P-scale might be useful to assess client's participation restrictions in diverse life situations. The p-scale is designed to assess and evaluate the participation of individuals with a health condition or disability (like SCI), especially conditions associated with stigmaand discrimination (van Brakel WH, Anderson AM & Mutatkar RK; 2006)

3.11 Data collection method:

The approval of the study protocol was taken from the Institutional Review Board (IRB) of the Bangladesh Health Professions Institute (BHPI). Written permission from the authorities of the specific unit of Centre for the Rehabilitation of the Paralyzed (CRP) was provided to conduct the study.

Data for this study was collected through face to face interview via interviewer administrated questionnaire.A self-developed socio-demographic questionnaire (including of socio-economic information, injury related information and health status) and participation scale were used to conduct the interview with the participants.

3.12 Data management and analysis:

There are many statistical methods that might be useful but the researcher used descriptive statistics. Descriptive statistics are those that describe, organise and summarise the data and include think as frequencies, percentages, and description of central tendency and descriptive of relative relation. The data analysis was done by statistical software named Statistical Package for Social Science (SPSS) version 20;by using descriptive statistic method and Microsoft excels spreadsheet.Each subject was defined by a code number and every question was conducted as a variable.

The code number and variables were labeled in a list in the variable view and the data input was performed in the data view of SPSS. The researcher checked the both questionnaire (demographic and participation scale questionnaire) and also data view for any unclear or missing or incorrect information. Then the data set was ready to analysis.

Descriptive statistics was used to estimate the information about socio-demographic status, socio-economic status, injury and health status; and also used to find out the frequency and percentage of these variables and the level of social participation of the participants. A chi-squared test, also written as x^2 test, is any statistical hypothesis test where the sampling distribution of the test statistic is a chi-squared distribution when the null hypothesis is true. Without other qualification, 'chi-squared test' often is used as short for Pearson's chi-squared test. The chi-squared test is used to determine whether there is a significant difference between the expected frequencies and the observed frequencies in one or more categories (Chi square tests PDF, 2018).Chi-square test was used to find out the association between demographic variables and social participation. Which associations were found as any according to the previous study or literature or article, those only focused in this study; whether statistically significant or not(Chi square tests PDF, 2018). This Chi-square test was done by using 2×2 table (crosstab) with P-value less than5% ($P<0.05$) for statistical significance(Chi square tests PDF, 2018). The presentation of data was organised in SPSS and in Microsoft Office Word. All data input were given within the variable of SPSS. Specific findings were described in bar, graph, pie chart and in different tables which were easily understandable for reader.

3.13 Quality control and Quality assurance:

The study was conducted through rigorous manner or trustworthiness. The entire study was conducted in a systemic way by following research steps under the supervision of an experienced supervisor. At the time of data collection and data analysis, the researcher never tries to influence the result by his own value or perspectives. The researcher accepted answers of the participants whether they would deliver.

The researcher collected the Bangla version of the Participation scale from the institute of Leprosy Mission Bangladesh. The researcher completed the piloting by interviewing 5 participants before starting the data collection.

3.14 Ethical consideration:

Ethical considerations implemented to avoid ethical problem. The researcher got permission from research supervisor and head of the department of Occupational Therapy of Bangladesh Health Professions Institute (BHPI), an academic institute of CRP to conduct the study. Researcher also got permission from CBR department to collect research participamnt’s address and contact number for data collection purpose. Information sheet and consent form were provided to each participants. Aim and objectives were clearly described in information sheet and consent form. Researcher informed verbally about the topic and purpose of the study to participant. The researcher assured them that confidentiality of personal information will be strictly maintained in future. The researcher ensured that the service of patient will not be hampered from their participation in this study. Participant had full right to withdraw their participation from this study at any time. The researcher also committed not to share the information given with others except the research supervisor. As the participants were informed by the information sheet about the study, so they provided their consent by the consent form. The information gathered from the participants anonymously. The researcher was available to answer any study related questions or inquiries from the participants. All sources cited and acknowledged appropriately. The field notes and answer sheet not shared or discussed with others.

CHAPTER 04 RESULT

4.1 Results with respect to the Socio-Demographic status

4.1.1 Table 1: Distribution of respondents by age, educational status, marital status, living environment

Socio-demographic characteristics of the respondents	n=70 Frequency (n)	n=70 Percent (%)
Age range		
18-30 years	17	24.3
31-40 years	17	24.3
41-50 years	19	27.1
51-60 years	11	15.7
61-70 years	6	8.6
Mean ± SD	41.91 ± 12.57	41.91 ± 12.57
Educational status		
Illiterate	1	1.4
Primary (class 1-5)	13	18.6
Secondary (class 6-10)	20	28.6
S.S.C. pass	15	21.4
H.S.C. pass	11	15.7
Graduate	10	14.3
Marital status		
Unmarried	18	25.7
Married	48	68.6
Separate	3	4.3
Divorced	1	1.4
Living area		
Rural	7	10.0
Urban	59	84.3
Semi-urban	4	5.7
Type of family		
Joint family	24	34.3
Single family	39	55.7
Living alone	7	10.0

The above table shows that, the total respondents were 70 (n=70) from 18-70 years with mean age of 41.91 (±12.57). There were 17 respondents (24.3%) from 18-30 years and another 17 respondents (24.3%) from 31-40 years, 19 respondents (27.1%) from 41-50 years,11 respondents (15.7%) from 51-60 years and 6 respondents (8.6%) from 61-70 years. Around 28.6% respondents (n=20) had secondary education (class 6-10) and 21.4% respondents (n=15) had S.S.C. education. Around 18.6% respondents (n=13) had primary education (class 1-5) and 15.7% respondents (n=11) had H.S.C. education. Around 14.3% respondents (n=10) had graduation on education and 1.4% respondents (n=1) had no education.

The above table also shows that, maximum respondents of this study lived in urban area. About 84.3% respondents (n=59) lived in urban area, 10.0% respondents (n=7) lived in rural area, and 5.7% respondents (n=4) lived in semi-urban area, among total participants (n=70).

About 25.7% respondents (n=18) were unmarried and 68.6% respondents (n=48) were married among 70 participants. Around 4.3% respondents (n=3) were separated from each other and 1.4% respondents (n=1) had divorced.

Besides, it was found from the study that, large number of respondents lived in single family. Around 55.7% (n=39) respondents lived in single family and nearly 34.3% (n=24) respondents lived in joint family among of total respondents. Only 10.0% (n=7) respondents lived alone.

4.1.2 Distribution of gender/sex of respondents

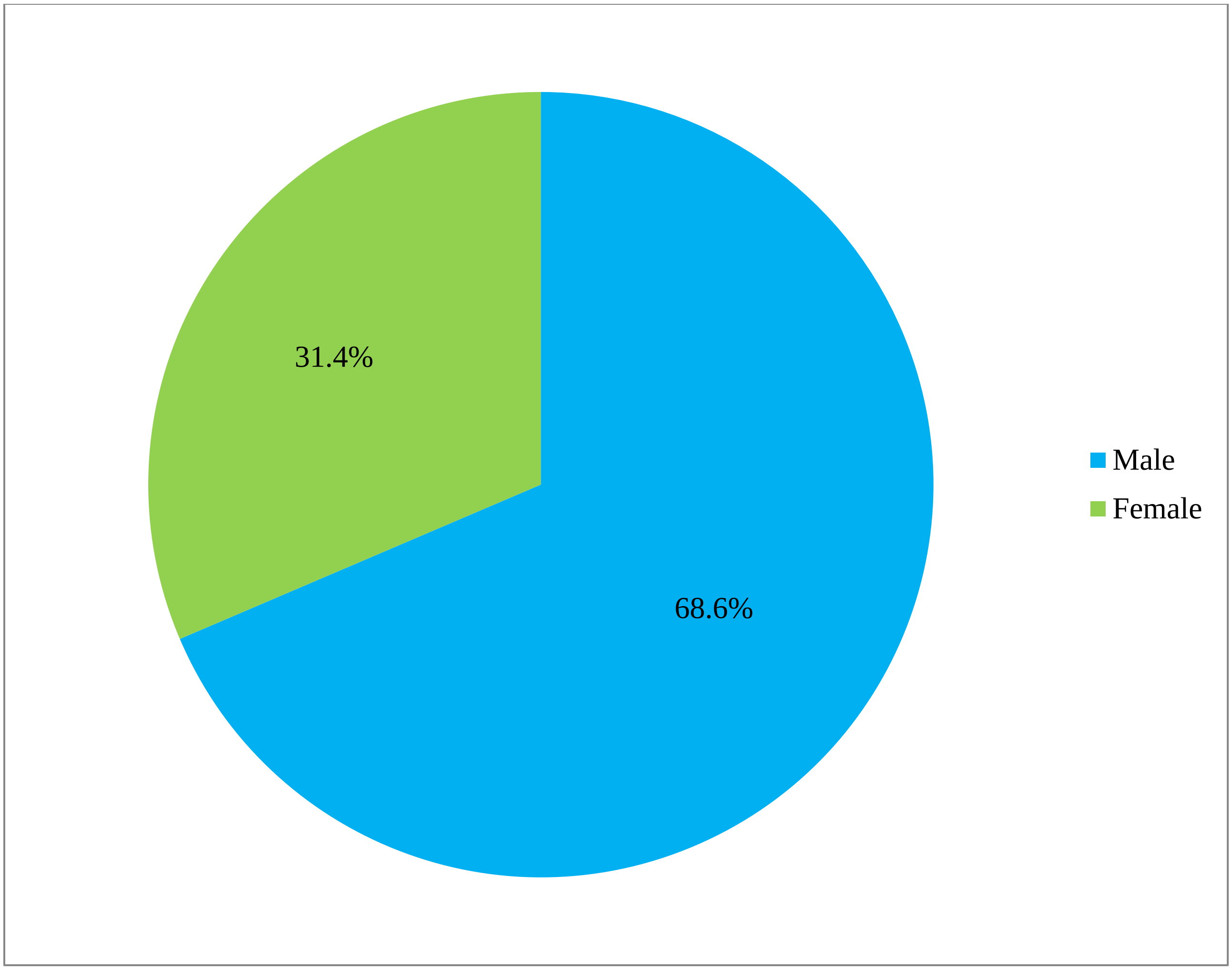


Figure 1: Distribution of sex between respondents

The study had counted both males and females according to subject matter of study. The figure 1 represents that out of 70 respondents 68.6% (n=48) were males and 31.4% (n=22) were females. The numbers of male respondents were higher than females.

4.1.3 Distribution of care-giver of respondents

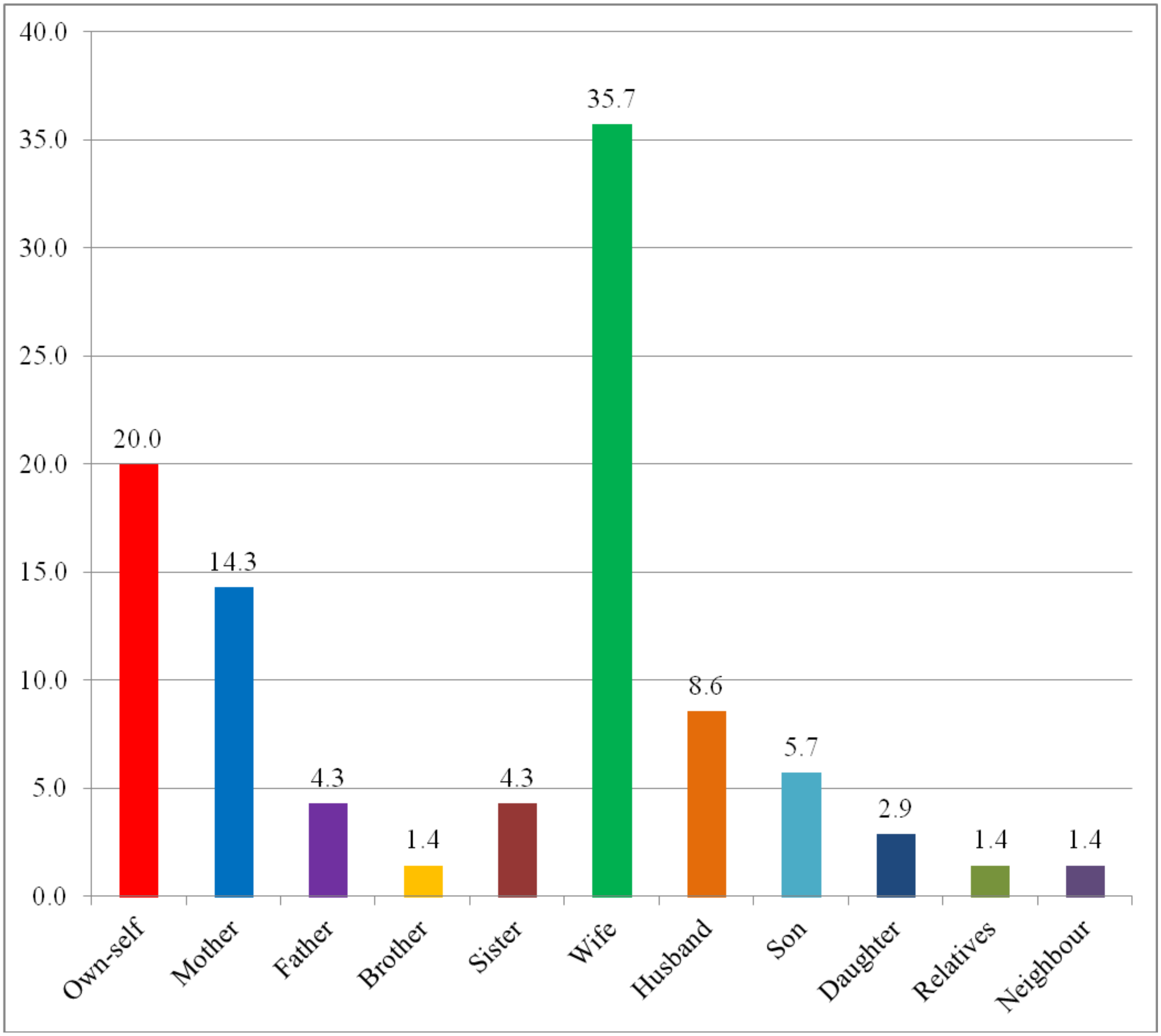


Figure 2: Statistics of care giver between respondents

The respondents were asked about their main care-giver at home. Different responses had found about this. It was found that, about 20% (n=14) respondents took own care by own self, 35.7% (n=25) respondents got care by wife, 14.3% (n=10) respondents got care by their mother. Besides, 8.6% (n=6) respondents got care from their husband, 4.3% (n=3) got care by their father, 5.7% (n=4) respondents got care by son and 2.9% (n=2) respondents got care by daughter. Care was provided by brother to 1.4% (n=1) respondents, by sister to 4.3% (n=3) respondents, by relatives to 1.4% (n=1) respondents and by neighbors to 1.4% (n=1) respondents among 100% respondents (n=70 persons).

4.1.4 Table 2: Distribution of respondents by occupation before injury, occupation after injury and assistive devices

Socio-demographic characteristics of the respondents	**n=70 Frequency (n)**	**n=70 Percent (%)**
Occupation before injury		
House-wife	8	11.4
Service holder	21	30.0
Own business	11	15.7
Day labor	10	14.3
Student	20	28.6
Current occupation		
House-wife	6	8.6
Day labor	1	1.4
Service holder	13	18.6
Own business	39	55.7
Student	4	5.7
Unemployment	7	10.0
Assistive device		
Use assistive device	64	91.4
Do not use assistive device	6	8.6

This table shows that, the respondents were asked about their occupation before injury, current occupation and assistive device. It was found that, before injury, respondents involved with different types of work. 11.4% (n=8) respondents were house-wife, 30.0% (n=21) respondents were service holder, 15.7% (n=11) respondents maintained own business, 14.3% (n=10) day labor, and 28.6% (n=20) respondents were student before their injury.

But after their injury, it was seen that, maximum respondents involved with own business. About 55.7% (n=39) respondents maintain own-business, 18.6% (n=13) respondents were service holder, 1.4% (n=1) respondents were day labor, 5.7% (n=4) respondents went back to their study. About 10.0% (n=7) respondents were unemployment

After injury and completing rehabilitation, it was seen that, significant number of respondents 91.4% (n=64) used assistive device in their community life to participate in different social events and about 8.6% (n=6) respondents do not use assistive device in the stage of community life.

4.1.5 Distribution of actual assistive device using by respondents

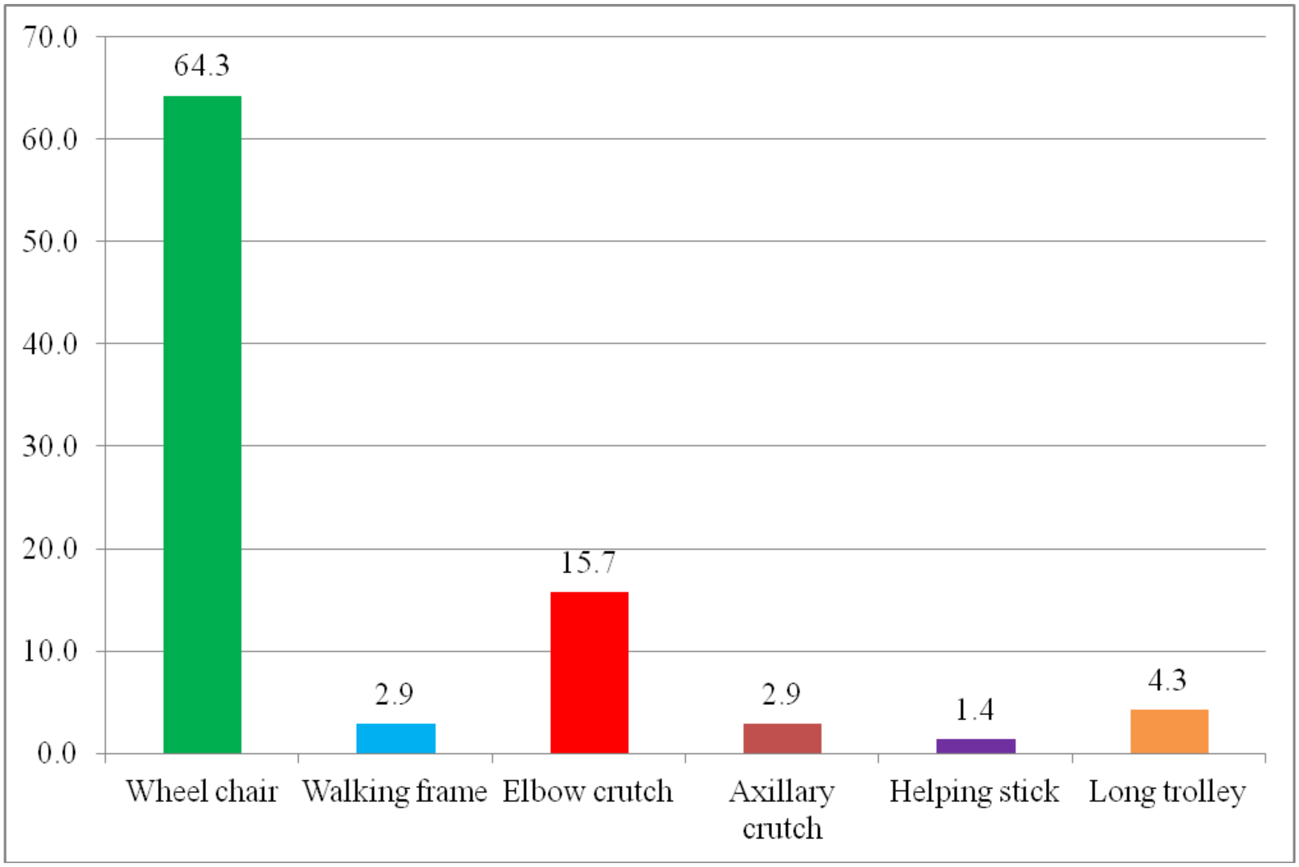


Figure 3: Statistics on actual using of assistive device

The respondents were asked about their assistive device and actual using assistive device in the community. Already, it was known that, about 91.4% (n=64) respondents use assistive device in their community life and 8.6% (n=6) respondents do not use assistive device. Then, it was found (from 64 respondents) that: as assistive device, wheel chair was used by 64.3% (n=45) respondents, walking frame was used by 2.9% (n=2) respondents, elbow crutch was used by 15.7% (n=11) respondents and axillary crutch was used by 2.9% (n=2) respondents in their own community. 1.4% (n=1) respondents were used helping stick and 4.3% (n=3) respondents were used long trolley as assistive device in the community.

4.2 Results with respect to the Socio-Economic status

4.2.1 Table 3: Distribution of respondents by main earning person of family, earning ability and monthly income

Socio-economic characteristics of the respondents	**n=70 Frequency (n)**	**n=70 Percent (%)**
Main earning person of family		
Own-self	19	27.1
Father	19	27.1
Brother	3	4.3
Wife	12	17.1
Husband	9	12.9
Son	6	8.6
Daughter	1	1.4
Relatives	1	1.4
Earning		
Have earning	52	74.3
Have no earning	18	25.7
Monthly income		
Below 5,000	2	2.9
5,001-10,000	18	25.7
10,001-15,000	14	20.0
15,001-20,000	5	7.1
20,001-25,000	5	7.1
25,000+	8	11.4
No income	18	25.7
Mean	14000 BDT	

The above table shows that, total respondents were 70 (n=70) with mean income of 14000 BDT and respondents were asked about their main earning person of family, about their earning ability and monthly income. It was found that among total participants, 27.1% (n=19) respondents were the main earning person for their own family. Besides, the main earning person of the family was father for 27.1% (n=19) respondents, brother for 4.3% (n=3) respondents, wife for 17.1% (n=12) respondents, husband for 12.9% (n=9) respondents, son for 8.6% (n=6) respondents, daughter for 1.4% (n=1) respondent and relatives for 1.4% (n=1) respondent.

It was also found that, among total participants (70 persons), significant number of respondents 74.3% (n=52) have own earning and about 25.7% respondents (18 persons) have no earning.

The respondents were also asked about their monthly income. It was known that, among total participants (n=70), 2.9% (n=2) respondents had monthly income in below 5000 taka, 25.7% (n=18) respondents had monthly income within 5001-10000 taka, 20.0% (n=14) respondents had monthly income within 10001-15000 taka. Around 7.1% (n=5) had monthly income within 15001-20000 taka and another 7.1 % (n=5) respondents had monthly income within 20001-25000 taka. About 11.4% (n=8) respondents had monthly income of more than 25000 taka. There were 25.7% (n=18) respondents have no earning.

4.2.2 Information about source of income of respondents

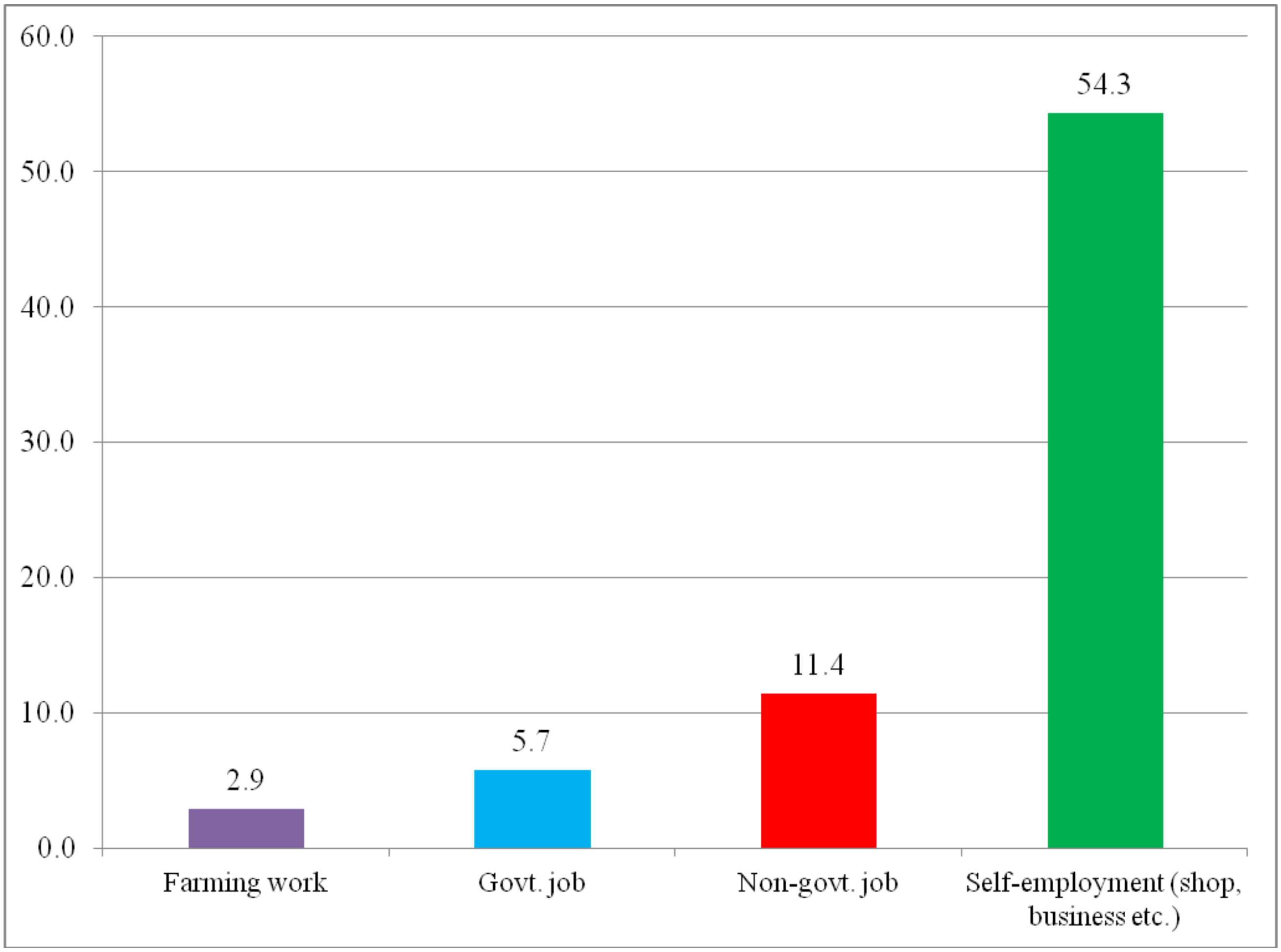


Figure 4: Statistics on source of income of respondents

This figure shows that, the total respondents were asked about their source of income. Different responses found from different respondents about this. Already, it was known that, about 74.3% respondents (52 persons) had earning and about 25.7% respondents (18 persons) had no earning, among 70 participants. It had seen that, among 52 earning participants, self-employment was the source of income for 54.3% (n=38) respondents, govt. job was the source of income for 5.7% (n=4) respondents, non govt. job was the source of income for 11.4% (n=8) respondents and farming work was the source of income for 2.9% (n=2) respondents.

4.2.3 Table 4: Distribution of respondents by main role in family and vocational training

Socio-economic characteristics of the respondents	**n=70 Frequency (n)**	**n=70 Percent (%)**
Main role in family		
Mother	14	20.0
Father	27	38.6
Brother	3	4.3
Wife	1	1.4
Husband	8	11.4
Son	9	12.9
Daughter	6	8.6
Own-career	2	2.9
Vocational training		
Taking vocational training	38	54.3
Taking no vocational training	32	45.7

The above table shows the statistics on the participant's main role in family and also about their vocational training. Among total participants (n=70) of this study, 38.6% (n=27) respondents played their main role as father in family, 20.0% (n=14) as mother, 11.4% (n=8) as husband and 12.9% (n=9) as son in family. Besides, 4.3% (n=3) respondents played their main role as brother in their family, 8.6% (n=6) as daughter, 1.4% (n=1) as wife in their family. Only 2.9% (n=2) respondents played their main role as self-career in their family.

It was found that, among total participants (n=70), maximum respondents took vocational training from CRP. About 54.3% (n=38) respondents took vocational training from CRP and about 45.7% (n=32) respondents didn't take any vocational training from CRP.

4.2.4 Actual taking of vocational training by respondents

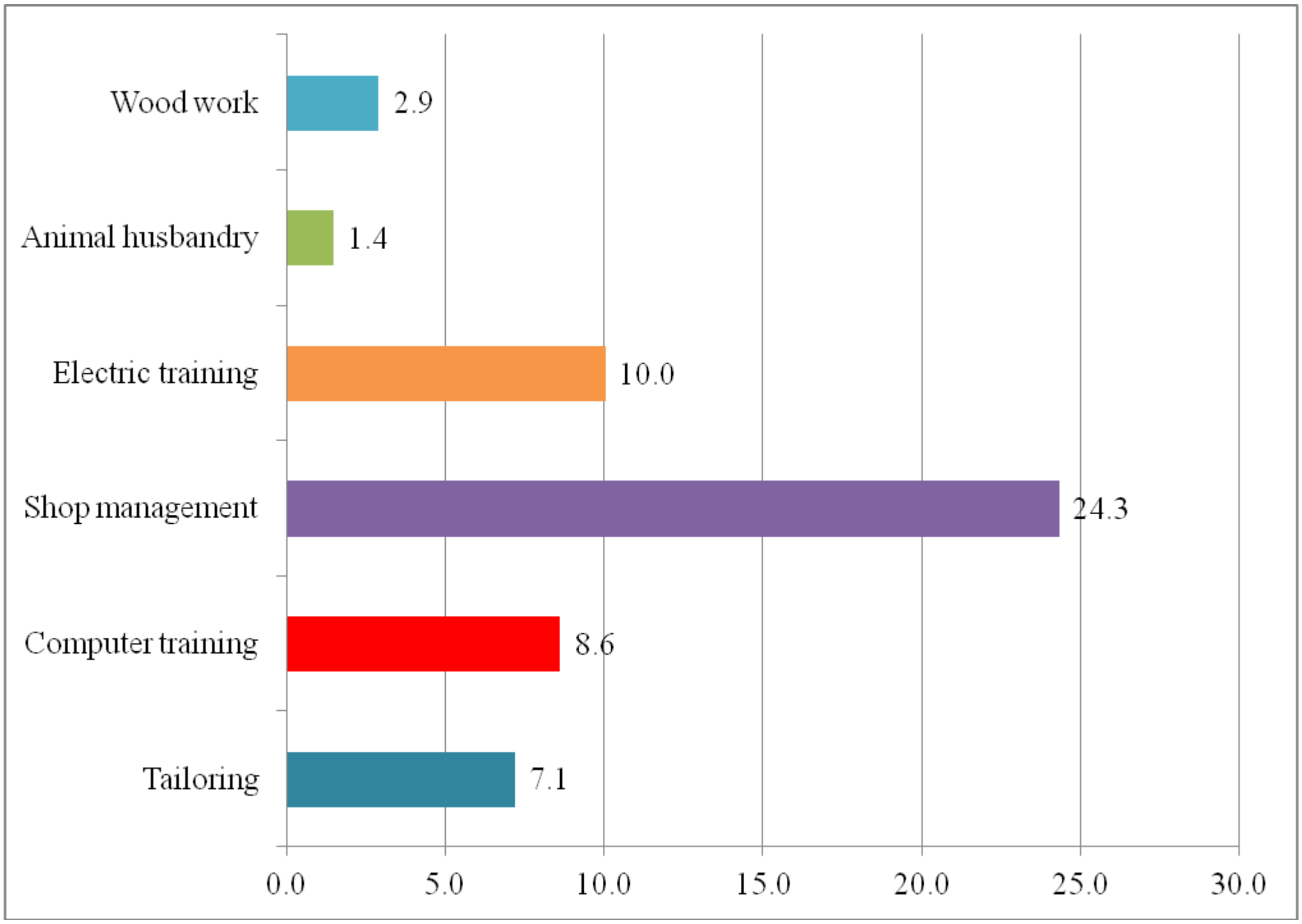


Figure 5: Statistics on taking actual vocational training by respondents

All respondents (n=70) were asked about their actual taking vocational training from CRP. Different person took different vocational training from CRP. It was already known that, from 70 participants, 54.3% (n=38) respondents took vocational training. Other 45.7% (n=32) respondents didn't take vocational training.

This figure shows that, among 38 respondents (who took vocational training), 24.3% (n=17) took shop management training, 10.0% (n=7) took electric training, 8.6% (n=6) took computer training, 7.1% (n=5) took tailoring training, 2.9% (n=2) took wood work training and 1.4% (n=1) took animal husbandry training. These respondents took those vocational training to lead their life comfortably in their community.

4.3 Injury related information of participants

4.3.1 Distribution of respondents by injury type

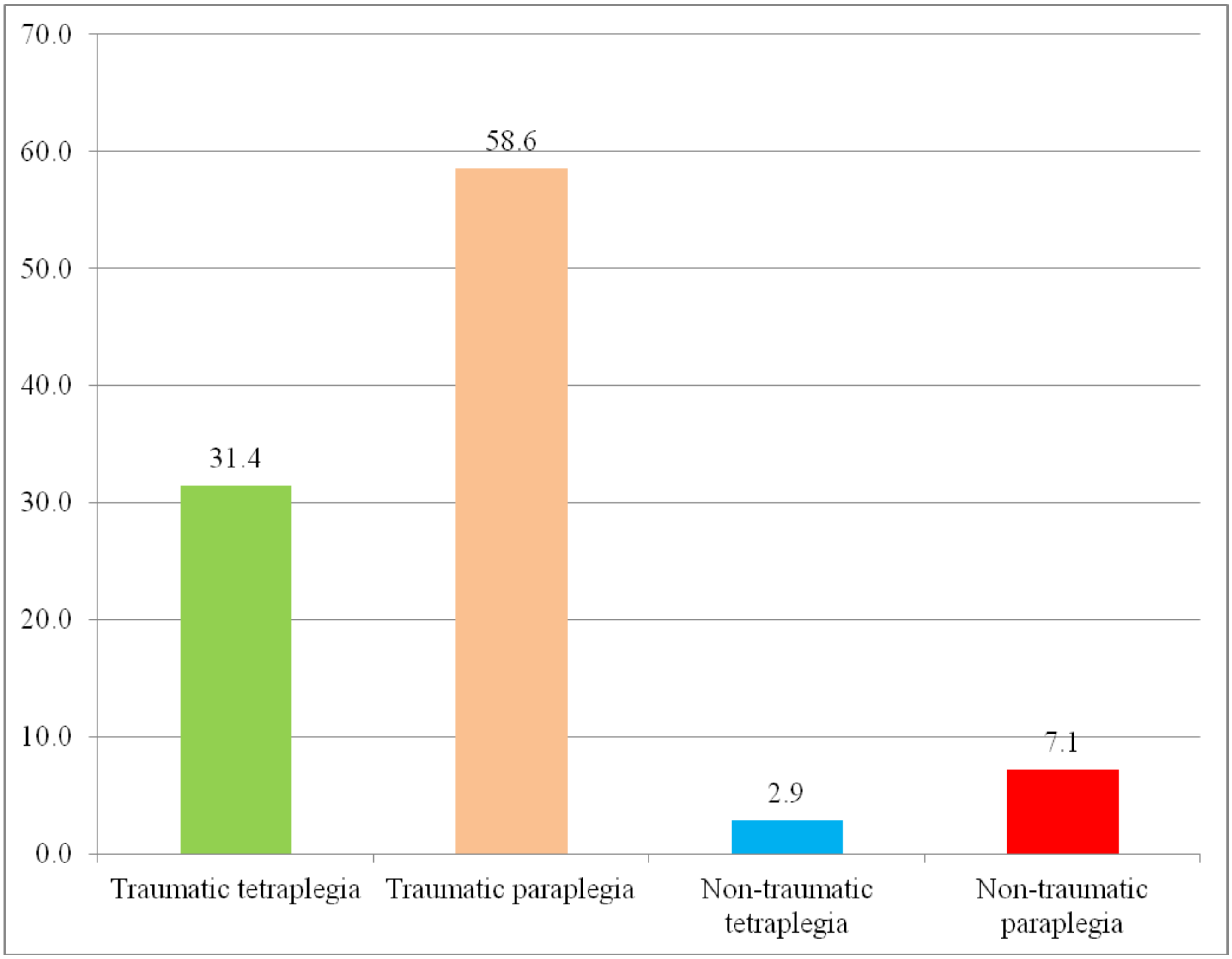


Figure 6: Injury type of the respondents

It was found that, among total participants (n=70), maximum respondents faced Spinal Cord Injury (SCI) with traumatic paraplegia. About 58.6% (n=41) respondents faced Spinal Cord Injury (SCI) with traumatic paraplegia, 31.4% (n=22) respondents faced SCI with traumatic tetraplegia. Besides, about 7.1% (n=5) respondents faced SCI with non-traumatic paraplegia and 2.9% (n=2) respondents faced SCI with non-traumatic tetraplegia.

4.3.2 Causes of injury of the respondents

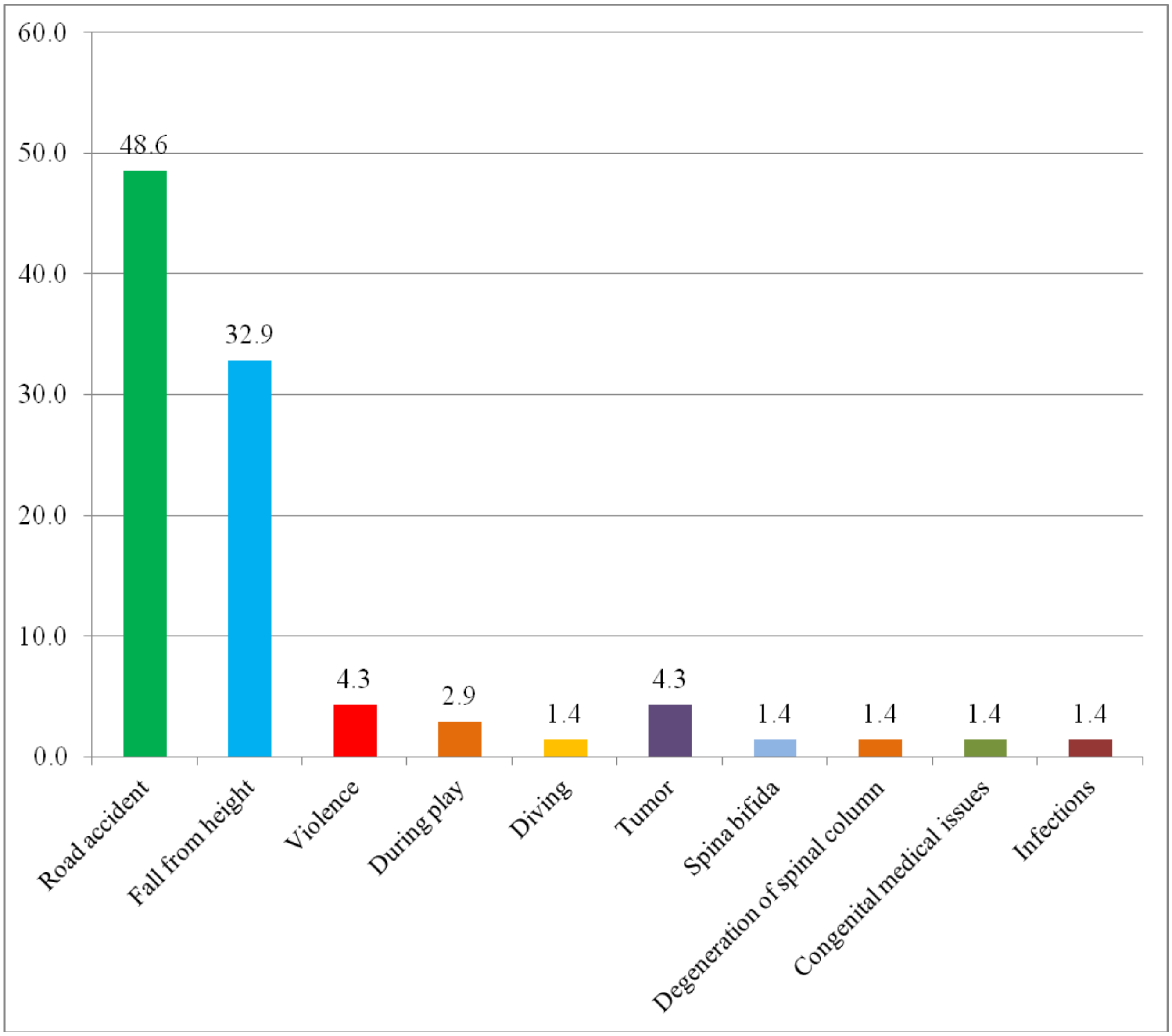


Fig 7: Reasons behind the injury of the participants

The respondents were asked by causes/reasons of their injury. Different reasons were found. But, the identifiable and most common reason in this study is road accident. Among total participants with SCI (n=70); as the cause, about 48.6% (n=34) respondents faced road accident, 32.9% (n=23) respondents faced fall from height, 4.3% (n=3) respondents faced violence, 2.9% (n=2) respondents faced SCI during play and 4.3% (n=3) respondents faced SCI by diving. These reasons indicate traumatic spinal cord injury.

Besides, among total participants with SCI (n=70); as the cause, about 4.3% (n=3) respondents faced SCI by tumor (in body), 1.4% (n=1) by spina bifida, 1.4% (n=1) by degenerative spinal column, 1.4% (n=1) by congenital medical issues and another 1.4% (n=1) by faced SCI infections. These reasons indicate non-traumatic spinal cord injury.

4.3.3 Distribution of respondents by their actual health complications

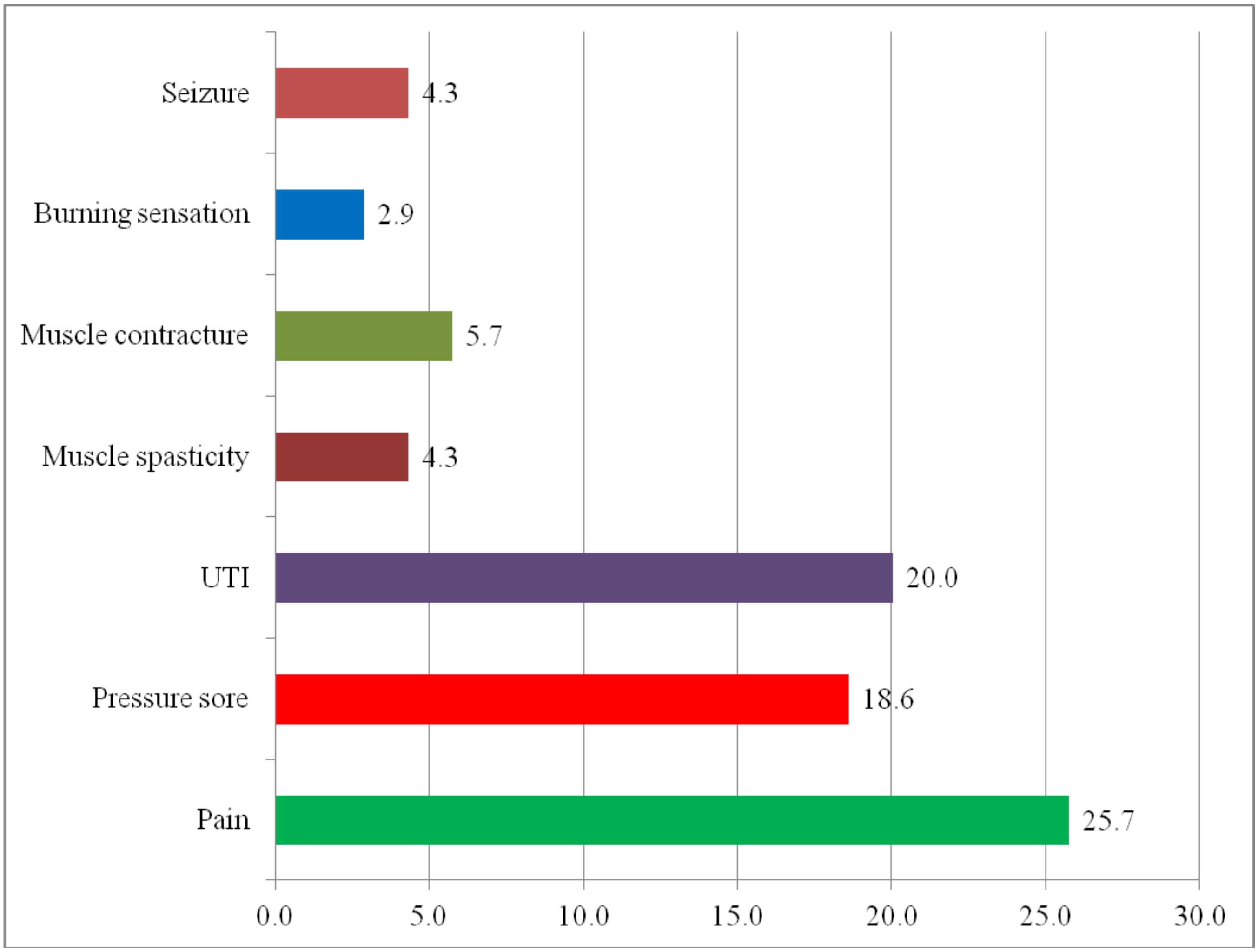


Figure 8: Statistics on actual health complications of respondents

It was already known that about 80% (n=56) respondents of this study had faced different types of health complications. Among them (n=56), about 25.7% (n=17) respondents had pain, 18.6% (n=13) had pressure sore, 20.0% (n=14) respondents had UTI (Urinary Tract Infection). Besides, about 4.3% (n=3) respondents had muscle spasticity,5.7% (n=4) respondents had muscle contracture, 2.9% (n=2) respondents had burning sensation and 4.3% (n=3) respondents had seizure as health complication.

4.4 The association between demographic factors (age, sex, current occupation, assistive device) and social participation

The study found that, there are associations between demographic factors (age, sex, current occupation, assistive device) and social participation. A participant's chi-square test was performed to show association between these variables.

4.5.1 Table 5:The association between participant's age and social participation(equal opportunities as peers to find work as peers)

Age range	**Social participation** **1.a. Equal opportunities as peers to find work**			**Total**
	Yes	Sometimes	No	
18-30 years	5 (29.4%)	3 (17.6%)	9 (52.9%)	17 (24.3%)
31-40 years	2 (11.8%)	2 (11.8%)	13 (76.5%)	17 (24.3%)
41-50 years	4 (21.1%)	5 (26.3%)	10 (52.6%)	19 (27.1%)
51-60 years	2 (18.2%)	0 (0.0%)	9 (81.8%)	11 (15.7%)
61-70 years	2 (33.3%)	2 (33.3%)	2 (33.3%)	6 (8.6%)
Total	15 (21.4%)	12 (17.1%)	42 (60.0%)	70 (100%)

This table is showed that, here is no strong association between the participant's age and social participation (in equal opportunities as peers to find work as peers), while n= 70.

4.5.2 Table 6:The association between participant's age and restriction of social participation

Age range	**Social participation**					**Total**	χ^2 **value**	**P Value**
	1.b. How big problem is it to the participant							
	No problem	Small	Medium	Large	Not applicable			
18-30 years	0 (0.0%)	2 (11.8%)	2 (11.8%)	8 (47.1%)	5 (29.4%)	17 (24.3%)	27.156	0.040
31-40 years	0 (0.0%)	0 (0.0%)	3 (17.6%)	12 (70.6%)	2 (11.8%)	17 (24.3%)	27.156	0.040
41-50 years	1 (5.3%)	0 (0.0%)	9 (47.4%)	5 (26.3%)	4 (21.1%)	19 (27.1%)	27.156	0.040
51-60 years	0 (0.0%)	0 (0.0%)	4 (36.4%)	5 (45.5%)	2 (18.2%)	11 (15.7%)	27.156	0.040
61-70 years	1 (16.7%)	0 (0.0%)	2 (33.3%)	0 (0.0%)	3 (50.0%)	6 (8.6%)	27.156	0.040
Total	2 (2.9%)	2 (2.9%)	20 (28.6%)	30 (42.9%)	16 (22.9%)	70 (100%)	27.156	0.040

This table is showed that, here is strong association between the participant's age and restrictions of social participation (in equal opportunities as peers to find work as peers). The founded χ^2 value is 27.156 and $p<0.040$, while $n= 70$.

4.5.3 Table 7:The association between participant's sex and social participation(equal opportunities as peers to find work as peers)

Sex	Social participation				Total	χ^2 value	P Value
	1.a. Equal opportunities as peers to find work						
	Yes	Sometimes	No	Irrelevant/I don't want to/I don't have to			
Male	14 (29.2%)	9 (18.8%)	25 (52.1%)	0 (0.0%)	48 (68.6%)	8.275	0.041
Female	1 (4.5%	3 (13.6%)	17 (77.3%)	1 (4.5%)	22 (31.4%)	8.275	0.041
Total	15 (21.4%)	12 (17.1%)	42 (60.0%)	1 (1.4%)	70 (100%)	8.275	0.041

It was found that, here is strong association between the participant's sex and social participation (in equal opportunities as peers to find work as peers). The founded χ^2value is 8.275 and p<0.041, while n= 70.

4.5.4Table 8:The association between participant's sex and restriction of social participation

Sex	Social participation					Total	χ^2 value	P Value
	1.b. How big problem is it to the participant							
	No problem	Small	Medium	Large	Not applicable			
Male	2 (4.1%)	1 (2.9%)	11 (22.9%)	20 (41.6%)	14 (29.1%)	48 (68.6%)	5.657	0.226
Female	0 (0.0%)	1 (4.5%)	9 (40.9%)	10 (45.5%)	2 (9.1%)	22 (31.4%)	5.657	0.226
Total	2 (2.8%)	2 (2.8%)	20 (28.6%)	30 (42.8%)	16 (22.9%)	70 (100%)	5.657	

This table is showed that, here is no strong association between the participant's sex and restrictions of social participation (in equal opportunities as peers to find work as peers). The founded χ^2 value is 5.657 and p<0.226, while n= 70.

4.5.5Table 9:The association between participant's sex and social participation(Ability to make visits outside of community as peers)

Sex	**Social participation**			**Total**
	2.a. Ability to make visits outside of community as peers			
	Yes	Sometimes	No	
Male	35 (72.9%)	7 (14.6%)	6 (12.5%)	48 (68.6%)
Female	10 (45.5%	9 (40.1%)	3 (13.6%)	22 (31.4%)
Total	45 (64.2%)	16 (22.9%)	9 (12.9%)	70 (100%)

It was found that, here is strong association between the participant's sex and social participation (in ability to make visits outside of community as peers), while n= 70.

4.5.6Table 10:The association between participant's sex and restriction of social participation

Sex	**Social participation** **2.b. How big problem is it to the participant**					**Total**	χ^2 **value**	**P Value**
	No problem	Small	Medium	Large	Not applicable			
Male	5 (10.4%)	3 (6.2%)	2 (4.2%)	3 (6.3%)	35 (72.9%)	48 (68.6%)	9.461	0.051
Female	6 (27.2%)	5 (22.7%)	1 (4.5%)	0 (0.0%)	10 (45.5%)	22 (31.4%)	9.461	0.051
Total	11 (15.7%)	8 (11.4%)	3 (4.3%)	3 (4.3%)	16 (22.9%)	70 (100%)	9.461	0.051

This table is showed that, here is no strong association between the participant's sex and restrictions of social participation (in ability to make visits outside of community as peers). The founded χ^2 value is 9.461 and $p<0.051$, while n= 70.

4.5.7Table 11:The association between participant’s sex and social participation(Socially activeness as peers)

Sex	Social participation			Total
	3.a. Socially activeness as peers			
	Yes	Sometimes	No	
Male	33 (68.8%)	10 (20.8%)	5 (10.4%)	48 (68.6%)
Female	6 (27.3%	8 (36.4%)	8 (36.4%)	22 (31.4%)
Total	39 (55.7%)	18 (25.7%)	13 (18.6%)	70 (100%)

It was found that, here is strong association between the participant’s sex and social participation (in socially activeness as peers), while n= 70.

4.5.8 Table 12:The association between participant’s sex and restriction of social participation

Sex	Social participation					Total	χ^2 value	P Value
	3.b. How big problem is it to the participant							
	No problem	Small	Medium	Large	Not applicable			
Male	10 (20.8%)	3 (6.2%)	1 (2.1%)	1 (2.1%)	33 (68.8%)	48 (68.6%)	11.852	0.018
Female	12 (54.5%)	3 (13.6%)	1 (4.5%)	0 (0.0%)	6 (27.3%)	22 (31.4%)	11.852	0.018
Total	22 (31.4%)	6 (8.6%)	2 (2.9%)	1 (1.4%)	39 (55.7%)	70 (100%)	11.852	0.018

This table is showed that, here is strong association between the participant's sex and restrictions of social participation (in socially activeness as peers). The founded χ^2 value is 11.852 and p<0.018, while n= 70.

4.5.9 Table 13:The association between participant's sex and social participation(Ability to visit public places as peers)

Sex	Social participation			Total
	4.a. Ability to visit public places as peers			
	Yes	Sometimes	No	
Male	35 (72.9%)	11 (22.9%)	2 (4.2%)	48 (68.6%)
Female	4 (18.2%	10 (45.5%)	8 (36.4%)	22 (31.4%)
Total	39 (55.7%)	21 (30.0%)	10 (14.3%)	70 (100%)

It was found that, here is heavy strong association between the participant's sex and social participation (in ability to visit public places as peers), while n= 70.

4.5.10Table 14:The association between participant's sex and restriction of social participation

Sex	Social participation					Total	χ^2 value	P Value
	4.b. How big problem is it to the participant							
	No problem	Small	Medium	Large	Not applicable			
Male	5 (10.4%)	5 (10.4%)	3 (6.2%)	0 (0.0%)	35 (72.9%)	48 (68.6%)	21.086	0.000
Female	12 (54.5%)	4 (18.2%)	2 (9.1%)	0 (0.0%)	4 (18.2%)	22 (31.4%)	21.086	0.000
Total	17 (24.3%)	9 (12.9%)	5 (7.1%)	0 (0.0%)	39 (55.7%)	70 (100%)	21.086	0.000

This table is showed that, here is heavy strong association between the participant's sex and restrictions of social participation (inability to visit public places as peers). The founded χ^2 value is 21.086 and p<0.000, while n= 70.

4.5.11Table 15:The association between participant's sex and social participation(Ability of comfortness in meeting with new people)

Sex	Social participation			Total
	5.a. Ability of comfortness in meeting with new people			
	Yes	Sometimes	No	
Male	39 (41.2%)	6 (12.5%)	3 (6.2%)	48 (68.6%)
Female	10 (45.5%	11 (50.0%)	1 (4.5%)	22 (31.4%)
Total	49 (70.0%)	17 (24.3%)	4 (6.7%)	70 (100%)

The founded information was that, here is heavy strong association between the participant's sex and social participation (in ability of comfortness in meeting with new people), while n= 70.

4.5.12Table 16:The association between participant's sex and restriction of social participation

Sex	Social participation					Total	χ^2 value	P Value
	5.b. How big problem is it to the participant							
	No problem	Small	Medium	Large	Not applicable			
Male	0 (0.0%)	6 (12.5%)	2 (4.2%)	1 (2.1%)	39 (81.2%)	48 (68.6%)	21.086	0.000
Female	1 (4.5%)	10 (45.5%)	1 (4.5%)	0 (0.0%)	10 (45.5%)	22 (31.4%)	21.086	0.000
Total	1 (1.4%)	16 (22.9%)	3 (4.3%)	1 (1.4%)	49 (70.0%)	70 (100%)	21.086	0.000

This table is showed that, here is heavy strong association between the participant's sex and restrictions of social participation (inability of comfortness in meeting with new people). The founded χ^2 value is 21.086 and p<0.000, while n= 70.

4.5.13Table 17:The association between participant's current occupation and social participation (Economical contribution ability to household as peers)

Current occupation	**Social participation**			
	1.a. Economical contribution ability to household as peers			
	Yes	Sometimes	No	**Total**
House-wife	0 (0.0%)	0 (0.0%)	6 (100.0%)	6 (8.6%)
Farmer	1 (100.0%)	0 (0.0%)	0 (0.0%)	1 (1.4%)
Govt. service holder	4 (100.0%)	0 (0.0%)	0 (0.0%)	4 (5.7%)
Non Govt. service holder	7 (77.8%)	1 (11.1%)	1 (11.1%)	9 (12.9)
Own business	28 (71.8%)	7 (17.9%)	4 (10.3%)	39 (55.7%)
Student	0 (0.0%)	0 (0.0%)	4 (100.0%)	4 (5.7%)
Unemployment (able to work)	0 (0.0%)	0 (0.0%)	4 (100.0%)	4 (5.7%)
Unemployment (unable to work)	0 (0.0%)	0 (0.0%)	3 (100.0%)	3 (4.3%)
Total	40	8	22	70 (100.0%)

The founded information was that, here is heavy strong association between the participant's current occupation and social participation (in economical contribution ability to household as peers), while n= 70.

4.5.14Table 18:The association between participant's Current occupation and restriction of social participation

Current occupation	**Social participation**					**Total**	χ^2 **value**	**P Value**
	1.b. How big problem is it to the participant							
	No problem	Small	Medium	Large	Not applicable			
House-wife	5 (83.3%)	1 (16.7%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	6 (8.6%)	89.829	0.000
Farmer	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (100.0%)	1 (1.4%)	89.829	0.000
Govt. service holder	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	4 (100.0%)	4 (5.7%)	89.829	0.000
Non Govt. service holder	0 (0.0%)	0 (0.0%)	0 0.0%)	2 (22.2%)	7 (77.8%)	9 (12.9%)	89.829	0.000
Own business	1 (2.6%)	5 (12.8%)	2 (5.1%)	3 (7.7%)	28 (71.8%)	39 (55.7%)	89.829	0.000
Student	4 (100.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	4 (5.7%)	89.829	0.000
Unemployment (able to work)	0 (0.0%)	0 (0.0%)	2 (50.0%)	2 (50.0%)	0 (0.0%)	4 (5.7%)	89.829	0.000
Unemployment (unable to work)	1 (33.3%)	0 (0.0%)	0 (0.0%)	2 (66.7%)	0 (0.0%)	3 (4.3%)	89.829	0.000
Total	11 (15.7%)	6 (8.6%)	4 (5.7%)	9 (12.9%)	40 (57.1%)	70 (100.0%)	89.829	0.000

This table is showed that, here is heavy strong association between the participant's current occupation and restrictions of social participation (ineconomical contribution ability to household as peers). The founded χ^2 value is 89.829 and $p<0.000$, while n= 70.

4.5.15Table 19:The association between participant’s current occupation and social participation (Maintaining long term relationship with life partner as peers)

Current occupation	**Social participation**				**Total**	χ^2 **value**	**P Value**
	2.a. Maintaining long term relationship with life partner as peers						
	Yes	Sometimes	No	Irrelevant/I don't want to/I don't have to			
House-wife	2 (33.3%)	2 (33.3%)	1 (16.7%)	1 (16.7%)	6 (8.6%)	32.783	0.049
Farmer	1 (100.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (1.4%)	32.783	0.049
Govt. service holder	1 (25.0%)	3 (75.0%)	0 (0.0%)	0 (0.0%)	4 (5.7%)	32.783	0.049
Non Govt. service holder	3 (33.3%)	1 (11.1%)	1 (11.1%)	4 (44.4%)	9 (12.9)	32.783	0.049
Own business	9 (23.1%)	11 (28.2%)	17 (43.6%)	2 (5.1%)	39 (55.7%)	32.783	0.049
Student	2 (50.0%)	0 (0.0%)	0 (100.0%)	2 (50.0%)	4 (5.7%)	32.783	0.049
Unemployment (able to work)	1 (25.0%)	2 (50.0%)	0 (100.0%)	1 (25.0%)	4 (5.7%)	32.783	0.049
Unemployment (unable to work)	2 (66.7)	1 (33.3%)	0 (0.0%)	0 (0.0%)	3 (4.3%)	32.783	0.049
Total	21 (30.0%)	20 (28.6%)	19 (27.1%)	10 (14.3%)	70 (100.0%)	32.783	0.049

The table is showed that, here is strong association between the participant’s current occupation and social participation (in maintaining long term relationship with life partner as peers). The founded χ^2 value is 32.783 and $p<0.049$, while n= 70.

4.5.16Table 20:The association between participant's Current occupation and restriction of social participation

Current occupation	**Social participation** **2.b. How big problem is it to the participant** No problem	Small	Medium	Large	Not applicable	**Total**	χ^2 **value**	**P Value**
House-wife	0 (0.0%)	0 (0.0%)	2 (33.3%)	1 (16.7%)	3 (50.0%)	6 (8.6%)	33.855	0.206
Farmer	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (100.0%)	1 (1.4%)	33.855	0.206
Govt. service holder	0 (0.0%)	0 (0.0%)	3 (75.0%)	0 (0.0%)	1 (25.0%)	4 (5.7%)	33.855	0.206
Non Govt. service holder	0 (0.0%)	1 (11.1%)	0 0.0%)	1 (11.1%)	7 (77.8%)	9 (12.9%)	33.855	0.206
Own business	6 (15.4%)	2 (5.1%)	6 (15.4%)	14 (35.9%)	11 (28.2%)	39 (55.7%)	33.855	0.206
Student	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	4 (100.0%)	4 (5.7%)	33.855	0.206
Unemployment (able to work)	1 (25.0%)	0 (0.0%)	0 (0.0%)	1 (25.0%)	2 (50.0%)	4 (5.7%)	33.855	0.206
Unemployment (unable to work)	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (33.3%)	2 (66.7%)	3 (4.3%)	33.855	0.206
Total	7 (10.0%)	3 (4.3%)	11 (15.7%)	18 (25.7%)	39 (44.3%)	70 (100.0%)	33.855	0.206

This table is showed that, here is no strong association between the participant's current occupation and restrictions of social participation (inmaintaining long term relationship with life partner as peers). The founded χ^2 value is 33.855 and p<0.206, while n= 70.

4.5.17Table 21:The association between participant’s assistive device and social participation (Hard working ability as peers)

Assistive device	**Social participation**			
	1.a. Hard working ability as peers			
	Yes	Sometimes	No	**Total**
Wheel chair	8 (17.8%)	17 (37.8%)	20 (44.4%)	45 (64.3%)
Walking frame	1 (50.0%)	1 (50.0%)	0 (0.0%)	2 (2.9%)
Elbow crutch	7 (63.6%)	0 (0.0%)	4 (36.4%)	11 (15.7%)
Axillary crutch	2 (100.0%)	0 (0.0%)	0 (11.1%)	2 (100.0%)
Helping stick	1 (100.0%)	0 (0.0%)	0 (0.0%)	1 (100.0%)
Long trolley	1 (33.3%)	0 (0.0%)	2 (66.7%)	3 (4.3%)
Total	23 (32.9%)	20 (28.6%)	27 (38.6%)	70 (100.0%)

The table is showed that, here is strong association between the participant’s current occupation and social participation (in hard working ability as peers), while n= 70.

4.5.18 Table 22:The association between participant’s assistive device and restriction of social participation

Assistive device	Social participation					Total	χ^2 value	P Value
	1.b. How big problem is it to the participant							
	No problem	Small	Medium	Large	Not applicable			
Wheel chair	1 (2.2%)	6 (13.3%)	18 (40.0%)	12 (26.7%)	8 (17.8%)	45 (64.3%)	31.842	0.131
Walking frame	0 (0.0%)	0 (0.0%)	1 (50.0%)	0 (0.0%)	1 (50.0%)	2 (2.9%)	31.842	0.131
Elbow crutch	0 (0.0%)	0 (0.0%)	1 (9.1%)	3 (27.3%)	7 (63.6%)	11 (15.7%)	31.842	0.131
Axillary crutch	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	2 (100.0%)	2 (2.9%)	31.842	0.131
Helping stick	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (100.0%)	1 (1.4%)	31.842	0.131
Long trolley	1 (33.3%)	0 (0.0%)	0 (0.0%)	1 (33.3%)	1 (33.3%)	3 (4.3%)	31.842	0.131
Not applicable	1 (16.7%)	1 (16.7%)	0 (0.0%)	1 (16.7%)	3 (50.0%)	6 (8.6%)	31.842	0.131
Total	3 (4.3%)	7 (10.0%)	20 (28.6%)	17 (24.3%)	23 (32.9%)	70 (100.0%)	31.842	0.131

This table is showed that, here is no strong association between the participant’s current occupation and restrictions of social participation (inhard working ability as peers). The founded χ^2 value is 31.842 and $p<0.131$, while n= 70.

4.5.19 Table 23:The association between participant’s assistive device and social participation (Acceptance of opinion in family discussion as peers)

Assistive device	Social participation				Total	χ^2 value	P Value
	2.a. Acceptance of opinion in family discussion as peers						
	Yes	Sometimes	No	Irrelevant/I don't want to/I don't have to			
Wheel chair	33 (73.3%)	8 (17.8%)	4 (8.9%)	0 (0.0%)	45 (64.3%)	49.376	0.000
Walking frame	1 (50.0%)	1 (50.0%)	0 (0.0%)	0 (0.0%)	2 (2.9%)	49.376	0.000
Elbow crutch	11 (100.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	11 (15.7%)	49.376	0.000
Axillary crutch	1 (50.0%)	0 (0.0%)	0 (0.0%)	1 (50.0%)	2 (2.9%)	49.376	0.000
Helping stick	0 (0.0%)	1 (100.0%)	0 (0.0%)	0 (0.0%)	1 (1.4%)	49.376	0.000
Long trolley	2 (66.7%)	0 (0.0%)	1 (33.3%)	0 (0.0%)	3 (4.3%)	49.376	0.000
Not applicable	5 (83.3%)	1 (16.7%)	0 (0.0%)	0 (0.0%)	6 (8.6%)	49.376	0.000
Total	53 (75.7%)	11 (15.7%)	5 (7.1%)	1 (1.4%)	70 (100.0%)	49.376	0.000

The table is showed that, here is heavy strong association between the participant’s current occupation and social participation (in **a**cceptance of opinion in family discussion as peers). The founded χ^2 value is 49.376 and $p<0.000$, while $n= 70$.

4.5.20 Table 24:The association between participant's assistive device and restriction of social participation

Assistive device	**Social participation** **2.b. How big problem is it to the participant**					**Total**	χ^2 **value**	**P Value**
	No problem	Small	Medium	Large	Not applicable			
Wheel chair	0 (0.0%)	2 (4.4%)	4 (8.9%)	6 (13.3%)	33 (73.3%)	45 (64.3%)	31.283	0.027
Walking frame	0 (0.0%)	0 (0.0%)	1 (50.0%)	0 (0.0%)	1 (50.0%)	2 (2.9%)	31.283	0.027
Elbow crutch	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	11 (63.6%)	11 (15.7%)	31.283	0.027
Axillary crutch	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	2 (100.0%)	2 (2.9%)	31.283	0.027
Helping stick	0 (0.0%)	1 (100.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (1.4%)	31.283	0.027
Long trolley	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (33.3%)	2 (66.7%)	3 (4.3%)	31.283	0.027
Not applicable	0 (0.0%)	1 (16.7%)	0 (0.0%)	0 (0.0%)	5 (83.3%)	6 (8.6%)	31.283	0.027
Total	0 (0.0%)	4 (5.7%)	5 (7.1%)	7 (10.0%)	54 (77.1%)	70 (100.0%)	31.283	0.027

This table is showed that, here is strong association between the participant's current occupation and restrictions of social participation (in acceptance of opinion in family discussion as peers). The founded χ^2 value is 31.283 and $p<0.027$, while n= 70.

4.6 Level of participation among people with SCI in community after completing rehabilitation

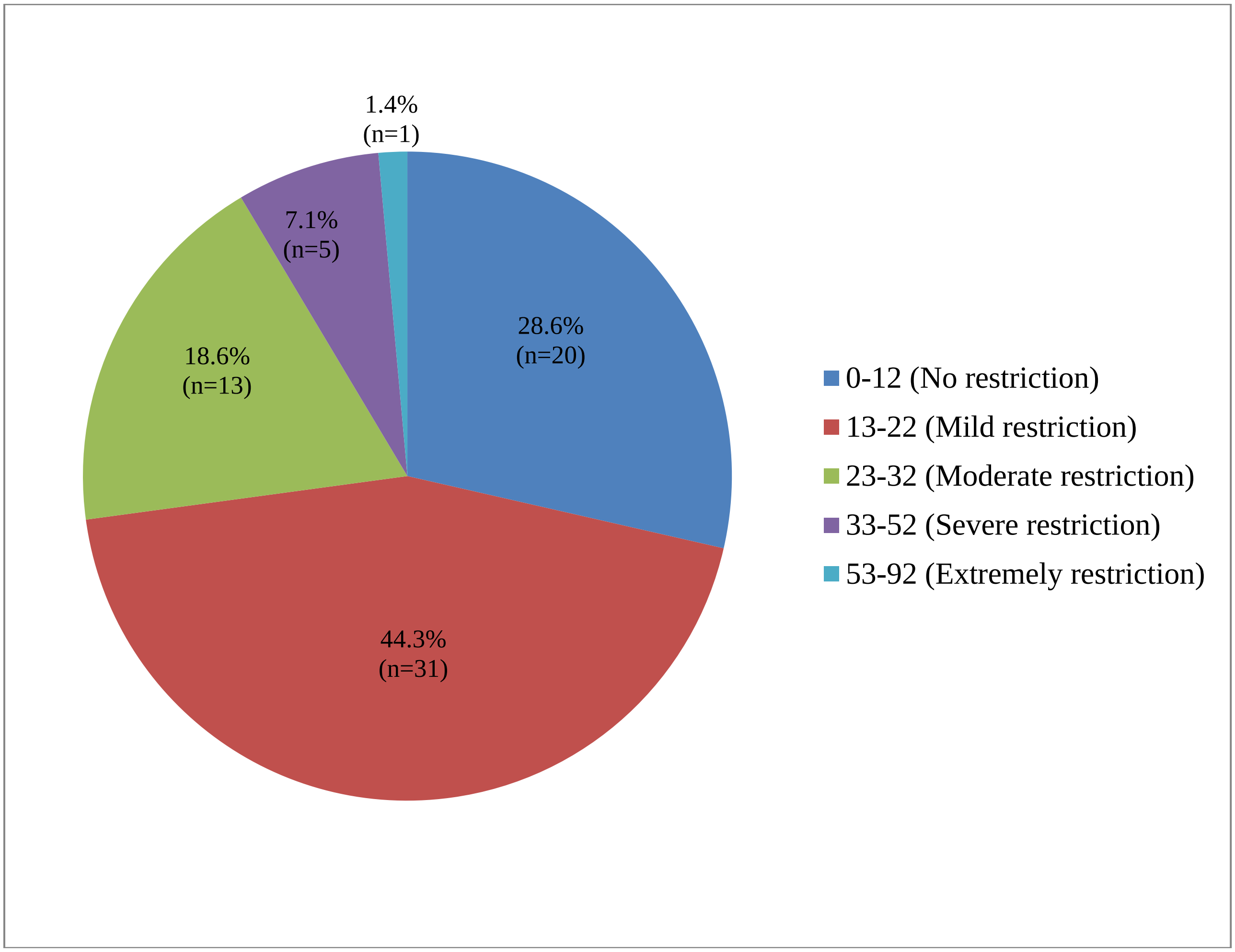


Figure 9: Statistic about level of participation of participant's with participation restriction score range

The total respondents (n=70) were asked about their social perception according to the questionnaire of participation scale. Different responses were found about these from the participant's. After completing data collection from the participant's, it was found that, about 28.6% (n=20) respondent's are in “No significant restriction stage (score: 0-12)”, about 43.3% (n=31) respondent's are in “Mild restriction stage (score: 13-22)”, and about 18.6% (n=13) respondent's are in “Moderate restriction stage (score: 23-32)”. Besides, about 7.1% (n=5) respondent's are in “Severe restriction stage (score: 32-52)” and about 1.4% (n=1) respondent's are in “Extremely restriction stage (score: 53-90)”

CHAPTER 05 DISCUSSION AND CONCLUSION

5.1 Discussion

The purpose of the study was to evaluate social participation among spinal cord injury people, living in the community of Dhaka city. Besides, the association was showed between the demographic factors and social participation of the participants through this study. In other hand, socio-economic status and health status are also showed through this study. For evaluating social participation, “participation scale (P-scale)” was used in the study, which is directly focused on social/community participation and the scale is validated for the people living with spinal cord injury.

In this study, the participant’s were 70, while 68.6% (n=48) were male and 31.4% (n=22) were female and age range was 18-70 years and participants mean±SD was 41.91 ±12.57. In another study in Nepal, total participants were 37, while male were 25 and another 12 were female and age range of them was 13-73 years, and participants mean±SD was32 (±13). (CY Scovil, MK Ranabhat, IB Craigheadand J Wee, 2007). But in another two study in Canada, sample was 145 (n) and male were 79% (n=115), female were 21% (n=30) and mean±SD was 48.7±17.4 approximately similar comparing with this study (Noonan et. Al., 2010). In one another study in UK, a sample of 357 people (response rate-44%)with SCI recruited through the British Columbia Paraplegic association. The mean agestandard deviation was 46.0±14.7years, mean time since SCI was 13.0±11.0 years, and 68% of therespondents were men; and respondents ranged in age from 17 to 98 years (Carpenter C, Forwell SJ, Jongbloed LE, Back-man CL. Community participation after spinal cord injury.Arch Phys Med Rehabil 2007;88:427-33)

In this study, 25.7% participants (n=18) were unmarried, 68.6% participants (n=48) were married, 4.3% participants were separated and 1.4% participants (n=1) were divorced. But in Canada, 31% (n=45) were unmarried, 55% (n=80) lead cohabiting life and 14% (n=20) were divorced (Noonan et al., 2010).

In this study, at educational level, about 28.6% participants (n=20) were in secondary level, 18.6% participants (n=13) were in primary level, 21.4% participants (n=15) were S.S.C. pass, 15.7% participants (n=11) were H.S.C. pass, 14.3% (n=10) were graduated and only 1.4% (n=1) were illiterate. In Canadian study, 43% (n=62) participants were completed education from high school, 49% (n=71) were completed education from college or under graduation and 8% (n=12) were graduate (Noonan et al., 2010).

In this study, it was seen that, after the injury, as current occupation; maximum respondents involved with own business. About 55.7% (n=39) respondents maintain own-business, 18.6% (n=13) respondents were service holder, 1.4% (n=1) respondents were day labor, 5.7% (n=4) respondents went back to their study. About 10.0% (n=7) respondents were unemployment

In this study, It was found that, among total participants (n=70), maximum respondents faced Spinal Cord Injury (SCI) with traumatic paraplegia. About 58.6% (n=41) respondents faced Spinal Cord Injury (SCI) with traumatic paraplegia, 31.4% (n=22) respondents faced SCI with traumatic tetraplegia. Besides, about 7.1% (n=5) respondents faced SCI with non-traumatic paraplegia and 2.9% (n=2) respondents faced SCI with non-traumatic tetraplegia. In another study at Nepal, among total participants (n=37), about 19 participants faced complete paraplegia, 10 participants faced incomplete paraplegia, 3 participants faced complete tetraplegia and 4 participants faced incomplete tetraplegia (CY Scovil, MK Ranabhat, IB Craigheadand J Wee, 2007).

In this study, as a evaluation of social participation of people living with SCI in their community, it was found that, about 28.6% (n=20) respondent's are in "No significant restriction stage (score: 0-12)", about 43.3% (n=31) respondent's are in "Mild restriction stage (score: 13-22)", and about 18.6% (n=13) respondent's are in "Moderate restriction stage (score: 23-32)". Besides, about 7.1% (n=5) respondent's are in "Severe restriction stage (score: 32-52)" and about 1.4% (n=1) respondent's are in "Extremely restriction stage (score: 53-90)". In other study at UK, No limitations to participation were experienced by18.5% of the respondents. Satisfaction with transportation wasassociated with owning one's own vehicle (P<001). Therewas overall satisfaction with access to community buildings(mean score range, 6.9–8.5; where 10 is most satisfied). Beingphysically active was important to a majority and 75% werecurrently engaged in physical activity(Carpenter C, Forwell SJ, Jongbloed LE, Back-man CL., 2007)

In this study, significant strong associations were found between demographic factors (age, sex, occupation and assistive device) and social participation of the participants. Associations were found between: participant's sex and social participation (in equal opportunities as peers to find work as peers), while $p<0.041$; participant's sex and social participation (in ability to make visits outside of community as peers), while $p<0.042$; participant's sex and social participation (in socially activeness as peers), while $p<0.003$; participant's sex and restrictions of social participation (in socially activeness as peers), while $p<0.018$; participant's sex and social participation (in ability to visit public places as peers), while $p<0.000$; participant's sex and restrictions of social participation (inability to visit public places as peers), while $p<0.000$; participant's sex and social participation (in ability of comfortness in meeting with new people), while $p<0.003$; participant's sex and restrictions of social participation (inability of comfortness in meeting with new people), while $p<0.000$; participant's current occupation and social participation (in economical contribution ability to household as peers), while $p<0.000$; participant's current occupation and restrictions of social participation (ineconomical contribution ability to household as peers), while $p<0.000$;participant's current occupation and social participation (in hard working ability as peers), while $p<0.045$;participant's current occupation and social participation (in **a**cceptance of opinion in family discussion as peers), while $p<0.000$;participant's current occupation and restrictions of social participation (in acceptance of opinion in family discussion as peers), while $p<0.027$.

5.2 Limitation:

- The researcher chose just 70 samples due to time limitation which is very small to generalize the result in all over the Bangladesh
- There are few literatures found about activity participation of people with SCI in the world.
- There is no related study found about level of participation of Bangladesh. Thus it is difficult to compare the study with the other research.
- In this study, only Dhaka city wasthe study area to generalize for wider population
- The questionnaire was developed only through searching sufficient literature but considering the context of the demography of the population a pilot study would substantial before developing questionnaire.

There are some limitations that should be kept in mind during conducting the study. The researcher always tried to consider these limitations. The following limitations have been identified during conducting the study.

- In this study purposive sampling was used to select the respondents. A small sample size is preferred when in-depth information is required. The findings of this study cannot be generalized to all people with SCI. Because, the sample size was small.
- Interview was conducted in Bangla. However the study is presented in English. Researcher had to translate interview information from Bengali to English. Sometimes it may difficult to discover actual meaning of some information from the data translation. But researcher tried heart and soul to give the actual information of the data in the study.
- There were limited resources and information available about participation because it is a new study within a Bangladeshi context.

5.3 Conclusions

This study provides a common metric of the impact of spinal cord injury in terms of community living. It also makes it possible to design and monitor the impact of health and health related interventions and for providing proper guidelines, techniques in terms of community living, in case of spinal cord injury. This study provides the basis for identifying levels of social participation of community living spinal cord injured people at individual perspective which open the need for foundations for country level participation data to inform policy and set-up rehabilitation. This study makes it possible to focus directly on level of social participation from community living spinal cord injured people.

On the other hand, proper rehabilitation is very necessary for people with SCI. It helps the people with SCI become as independent as possible and to attain the best possible quality of life and increase their participation in community.The findings of the study identified that there is a significant association between social participation and demographic status of the participants. However it should be considered that it is necessary to provide more information during the rehabilitation period. It is recommended that occupational therapist involved in the rehabilitation of people with SCI in Bangladesh should pay greater attention to the perceived and experienced restrictions in participation and be skilled to assist stroke survivors and their family members to identify and overcome these participation restrictions. If we increase awareness among the community people to enhance accessibility and well transportation system for the respondents which helps them to increase participation level in community and then this study will be helpful for thepeople with SCI.

5.4 Recommendation:

The researcher’s recommendation is that, OTs needs to study this topic in depth. This may involve:

- A survey to discover a people with SCI satisfaction about their active participation after SCI.
- Experiences of men and women with SCI to adjust to their previous participation in their own community after SCI.
- Find out the value of qualified Occupational Therapists and Occupational Therapy student’s practicing purposeful activity during rehabilitation period
- Researcher also recommends that OTs need to study on find out the level of community/social participation in different areas like as GBS, head injury etc.
- Further research should be conducted with a large numbers of participants on this study design. If researcher conducts the study with large samples then it will be easy to generalize the result.

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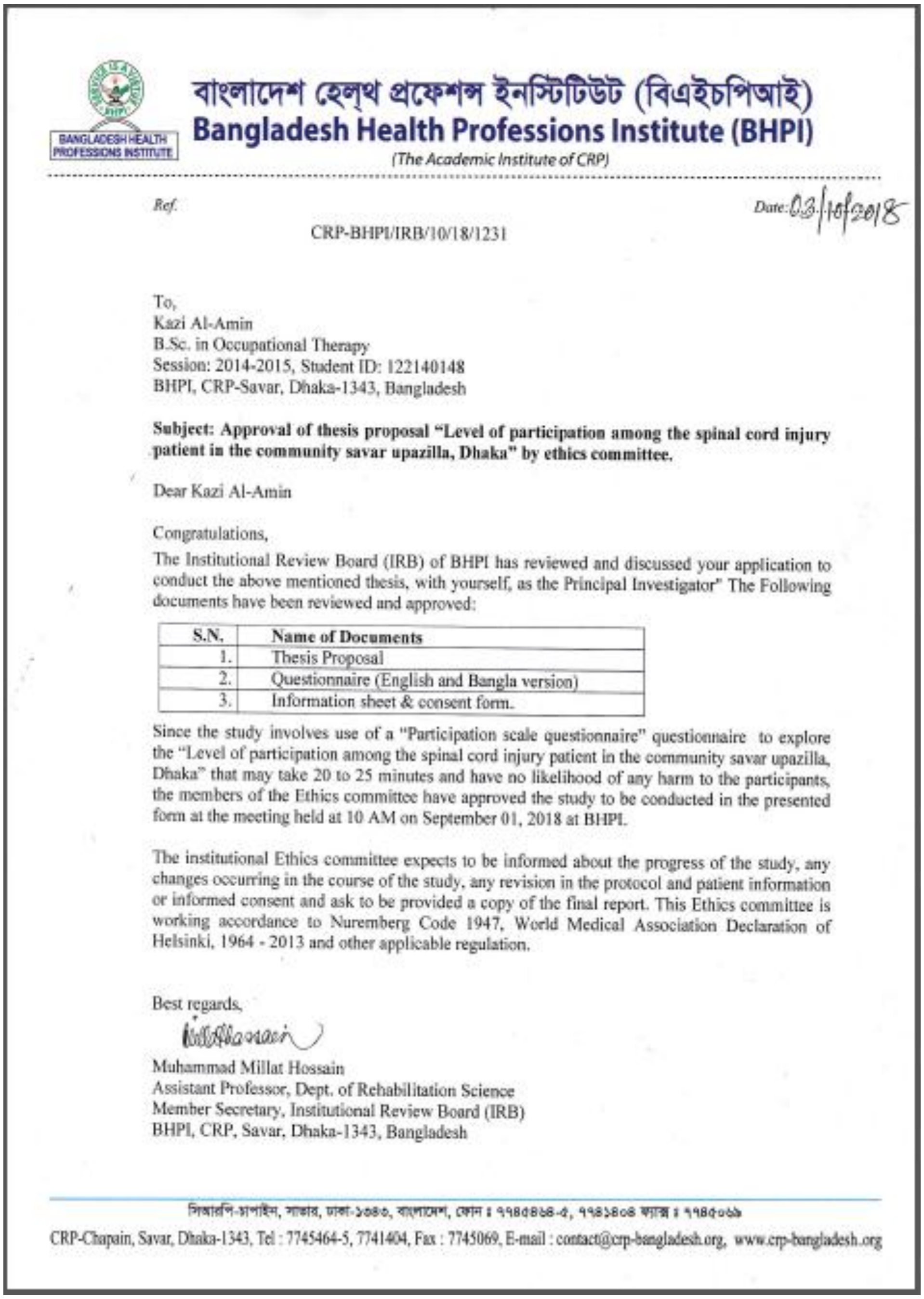
APPENDIX: I

Approval letter from IBR



বাংলাদেশ হেল্‌থ প্রফেশন্স ইনস্টিটিউট (বিএইচপিআই)
Bangladesh Health Professions Institute (BHPI)
(The Academic Institute of CRP)

Ref. CRP-BHPI/IRB/10/18/1231 Date: 03/10/2018

To,
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Session: 2014-2015, Student ID: 122140148
BHPI, CRP-Savar, Dhaka-1343, Bangladesh

Subject: Approval of thesis proposal "Level of participation among the spinal cord injury patient in the community savar upazilla, Dhaka" by ethics committee.

Dear Kazi Al-Amin

Congratulations,

The Institutional Review Board (IRB) of BHPI has reviewed and discussed your application to conduct the above mentioned thesis, with yourself, as the Principal Investigator" The Following documents have been reviewed and approved:

S.N.	Name of Documents
1.	Thesis Proposal
2.	Questionnaire (English and Bangla version)
3.	Information sheet & consent form.

Since the study involves use of a "Participation scale questionnaire" questionnaire to explore the "Level of participation among the spinal cord injury patient in the community savar upazilla, Dhaka" that may take 20 to 25 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 10 AM on September 01, 2018 at BHPI.

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

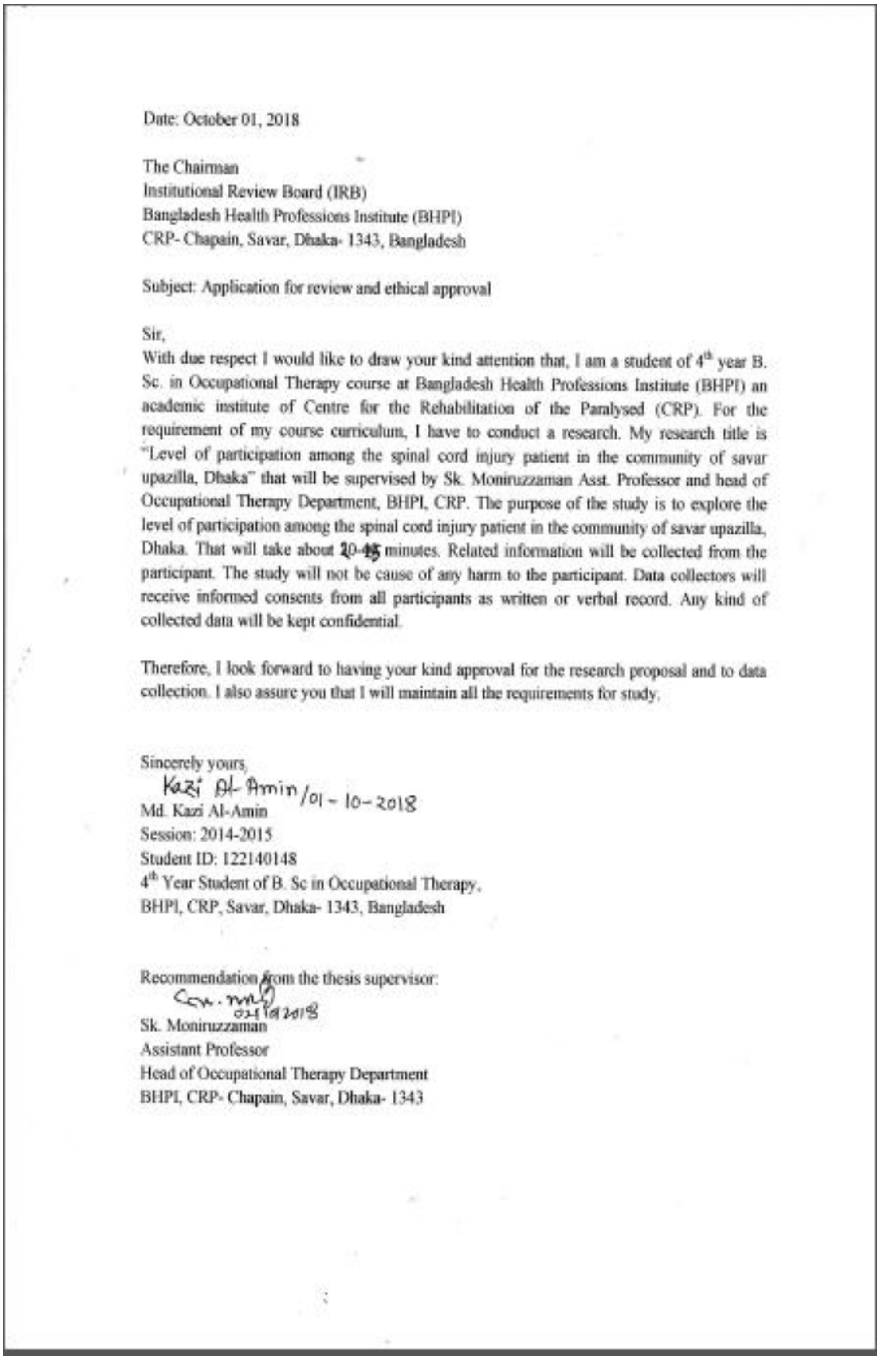
Best regards,

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

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

APPENDIX: II

Permission letter from IBR



Date: October 01, 2018

The Chairman
Institutional Review Board (IRB)
Bangladesh Health Professions Institute (BHPI)
CRP- Chapain, Savar, Dhaka- 1343, Bangladesh

Subject: Application for review and ethical approval

Sir,
With due respect I would like to draw your kind attention that, I am a student of 4th year B. Sc. in Occupational Therapy course at Bangladesh Health Professions Institute (BHPI) an academic institute of Centre for the Rehabilitation of the Paralysed (CRP). For the requirement of my course curriculum, I have to conduct a research. My research title is "Level of participation among the spinal cord injury patient in the community of savar upazilla, Dhaka" that will be supervised by Sk. Moniruzzaman Asst. Professor and head of Occupational Therapy Department, BHPI, CRP. The purpose of the study is to explore the level of participation among the spinal cord injury patient in the community of savar upazilla, Dhaka. That will take about 20-45 minutes. Related information will be collected from the participant. The study will not be cause of any harm to the participant. Data collectors will receive informed consents from all participants as written or verbal record. Any kind of collected data will be kept confidential.

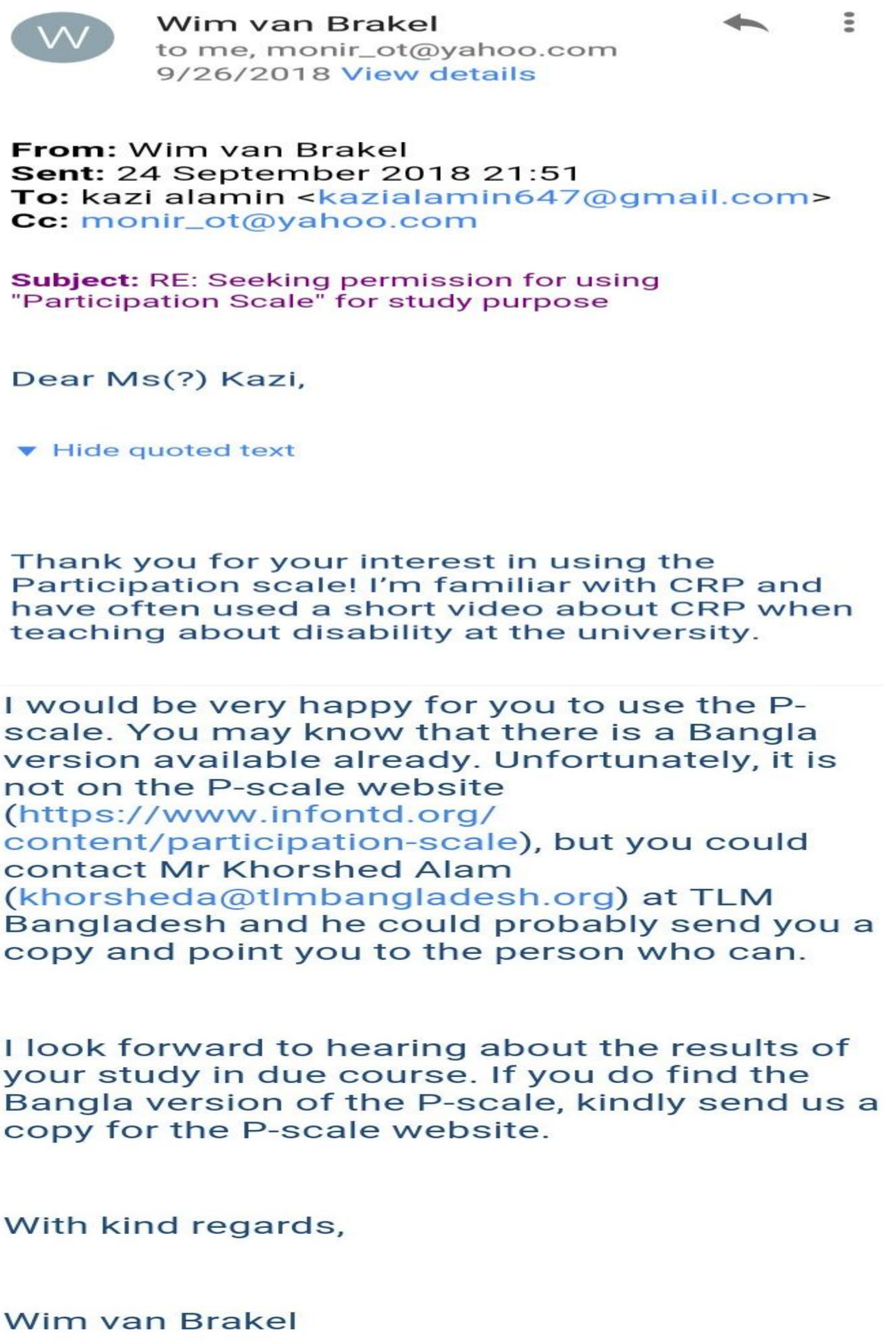
Therefore, I look forward to having your kind approval for the research proposal and to data collection. I also assure you that I will maintain all the requirements for study.

Sincerely yours,
Kazi Al-Amin/01-10-2018
Md. Kazi Al-Amin
Session: 2014-2015
Student ID: 122140148
4th Year Student of B. Sc in Occupational Therapy,
BHPI, CRP, Savar, Dhaka- 1343, Bangladesh

Recommendation from the thesis supervisor:
০২/১০/২০১৮
Sk. Moniruzzaman
Assistant Professor
Head of Occupational Therapy Department
BHPI, CRP- Chapain, Savar, Dhaka- 1343

APPENDIX: III

Author permission letter for Participation Scale version 6.0



Wim van Brakel
to me, monir_ot@yahoo.com
9/26/2018 View details

From: Wim van Brakel
Sent: 24 September 2018 21:51
To: kazi alamin <kazialamin647@gmail.com>
Cc: monir_ot@yahoo.com

Subject: RE: Seeking permission for using "Participation Scale" for study purpose

Dear Ms(?) Kazi,

Thank you for your interest in using the Participation scale! I'm familiar with CRP and have often used a short video about CRP when teaching about disability at the university.

I would be very happy for you to use the P-scale. You may know that there is a Bangla version available already. Unfortunately, it is not on the P-scale website (https://www.infontd.org/content/participation-scale), but you could contact Mr Khorshed Alam (khorsheda@tlmbangladesh.org) at TLM Bangladesh and he could probably send you a copy and point you to the person who can.

I look forward to hearing about the results of your study in due course. If you do find the Bangla version of the P-scale, kindly send us a copy for the P-scale website.

With kind regards,

Wim van Brakel

APPENDIX: IV

Information Sheet (English)

Introduction

I amKazi Al-Amin, B.Sc. in Occupational Therapy student of Bangladesh Health Professions Institute(BHPI), have to conduct a thesis as a part of this Bachelor course, under thesis supervisor, Sk, Moniruzzaman. You are going to have details information about the study purpose, data collection process, ethical issues.You do not have to decide today whether or not you will participate in the research. Before you decide, you can talk to anyone you feel comfortable with about the research. If this consent form contains some words that you do not understand, please ask me to stop. I will take time to explain.

Background and Purpose of the study

People with spinal cord injury, who have completed their rehabilitation program from CRP and after rehabilitation program who are living in their own community (in Dhaka city)for at least 6 months, are cordially invited to participate in this thesis. As a part of this, you are also a participant of this thesis and also invited to participate in this thesis. You have also awarded that, the main goal of Occupational Therapy is to engage the people in their daily life activities, social activities and Occupational activities as much as possible. Social participation in own community for People with spinal cord injury, who are completing rehabilitation program from CRP are very important and valuable, which helps to lead a better life for them in their own community. After rehabilitation, in the stage of community living, it is unknown that, how much activeness are creating in the people with SCI in their social participation, and restrictions of participation are also be unknown. The general aim of this thesis is to evaluate the social participation among people with SCI living in Dhaka city and also to measure the participation restrictions, which they face in their social participation. Your participation will be very helpful to fulfill the aim of this thesis.

Research related information

The research related information will be discussed with you throughout the information sheet before taking your signature on consent form. If the participant is interested to participate in the thesis, so that participant would be singed in the consent form. If you confirmed your participation, so that a copy of data collection paper will be provided. Then a volunteer team of researcher will go to the participant in the giving time of participant to collect data throughout the data collection paper. In this thesis, your participation would be voluntary. If you are not interested, so that you cannot participate. After participation, if you wish, you can remove your participation without any explanation to the researcher. And for this, the participant cannot be suffered with CRP, treatment facilities of CRP and also with other friendly organizations of CRP. The survey questionnaire will be distributed and collected by Kazi Al-Amin. If you do not wish the questions included in the survey, you may skip them and move on to the next question. The information recorded is confidential, your name is not being included on the forms, only a number will identify you, and no one else except Sk, Moniruzzaman, Supervisor of the study will have access to this survey.

Benefits and risks of participation

For participating in the thesis, you do not get facilities directly. We are hopeful that, which informations are identified through the thesis, all of those will be helpful to develop the treatment procedure and through those information's, therapist will be aware about all participants experiences. There are no any others risks in this participation.

Confidentiality of the participation

Through singing the consent form, permission will be provided to the researcher to use the participant's personal information for this research. Every information will be kept with confidential and any information cannot be mentioned the participants identity in this research.

Always key sign will be used to focus participants information. Only researcher get access to see the real information of the participants and every data of participants will be kept in drawer by locking to maintain confidentiality. It is hopeful that, the result and information are published in different forum research project. But any information cannot be presented, that can mention you. Primarily, data has collected through data collection paper.

Who to Contact

If you have any questions, you can ask me now or later. If you wish to ask questions later, you may contact any of the following:Kazi Al-Amin, Bachelor science in Occupational Therapy, Department of Occupational Therapy, e-mail: monikamoni.ot.edu@gmail.com, Cell phone-01927228603. This proposal has been reviewed and approved by Institutional Review Board (IRB), Bangladesh Health Professions Institute (BHPI), CRP-Savar, Dhaka-1343, Bangladesh, which is a committee whose task it is to make sure that research participants are protected from harm. If you wish to find about more about the IRB, contact Bangladesh Health Professions Institute (BHPI) (contact:7745464-5), CRP-Savar, Dhaka-1343, Bangladesh. You can ask me any more questions about any part of the research study, if you wish to. Do you have any questions?

Can you withdraw from this study:

You can cancel any information collected for this research project at any time. After the cancellation, we expect permission from the information whether it can be used or not.

APPENDIX: V

অংশগ্রহণকারীদের তথ্য পত্র

বাংলাদেশ হেল্‌থ প্রফেশন্স ইনষ্টিটিউট (বিএইচপিআই)

অকুপেশনাল থেরাপি বিভাগ

সিআরপি– চাপাইন, সাভার, ঢাকা–১৩৪৩.

টেলিঃ ০২-৭৭৪৫৪৬৪–৫,৭৭৪১৪০৪, ফ্যাক্সঃ ০২-৭৭৪৫০৬

কোড নংঃ

অংশগ্রহণকারীদের তথ্যপত্র

গবেষনার বিষয়ঃ ‘‘ঢাকা শহরে বসবাসকারী মেরুরুজ্জুতে আঘাত গ্রস্থ মানুষের সামাজিক অংশগ্রহণ এর মূল্যায়ন” ।

গবেষকঃ কাজী আল-আমিন, বি.এস.সি ইন অকুপেশনাল থেরাপি (৪র্থ বর্ষ),সেশনঃ২০১৪-২০১৫ ইং, বাংলাদেশ হেলথ্ প্রফেশন্স ইনস্টিটিউট (বিএইচপিআই), সাভার,ঢাকা- ১৩৪৩

তত্ত্বাবধায়কঃ শেখ মনিরুজ্জামান, সহকারী অধ্যাপক ও বিভাগীয় প্রধান, অকুপেশনালথেরাপি বিভাগ, বাংলাদেশ হেল্‌থ প্রফেশন্স ইনস্টিটিউট ।

গবেষনার স্থানঃ ঢাকা শহরে বসবাসরত মেরুরুজ্জুতে আঘাত গ্রস্থ মানুষদের এলাকা (মিরপুর, ধানমন্ডি, লালবাগ, সুত্রাপুর, কোতোয়ালী, সাভার, আশুলিয়া, ধামরাই, দোহার, নওয়াবগঞ্জ, গাবতলী, শ্যমলী, কাটাবন, ফার্মগেট ইত্যাদী) ।

পর্ব ১ তথ্যপত্রঃ

ভূমিকাঃ

আমি কাজী আল-আমিন, ঢাকা বিশ্ববিদ্যালয়ে চিকিৎসা অনুষদের অধীনে বাংলাদেশ হেল্‌থ প্রফেশন্স ইনস্টিটিউটে বি.এস.সি.ইন অকুপেশনাল থেরাপি বিভাগে ৪র্থ বর্ষের ছাত্র হিসেবে স্নাতক শিক্ষাকার্যক্রম (২০১৪-২০১৫ ইং) সেশনে অধ্যয়নরত আছি ।বিএইচপিআই থেকে অকুপেশনাল থেরাপি বি.এস.সি শিক্ষাকার্যক্রমটি সম্পন্ন করার

জন্য একটি গবেষণা প্রকল্প পরিচালনা করা বাধ্যতামূলক। এই গবেষণা প্রকল্পটি অকুপেশনাল থেরাপি বিভাগের সহকারী অধ্যাপক ও বিভাগীয় প্রধান শেখ মনিরুজ্জামানএর তত্ত্বাবধায়নে সম্পন্ন করা হবে। এইতথ্যপত্রের মাধ্যমে গবেষণার প্রকল্পটির উদ্দেশ্য, উপাত্ত সংগহের প্রণালী ও গবেষণাটির সাথেসংশ্লিস্ট বিষয় কিভাবে রক্ষিত হবে তা বিস্তারিতভাবে গবেষণায় অংশগ্রহণকারী ব্যক্তির নিকট উপস্থাপন করা হবে। যদি এই গবেষণায় অংশগ্রহন করতে আপনি ইচ্ছুক থাকেন, সেক্ষেত্রে এই গবেষণার সম্পৃক্ত বিষয় সম্পর্কে স্বচ্ছ ধারনা থাকলে সিদ্ধান্ত গ্রহন সহজতর হবে। অবশ্য এখন আপনার অংশগ্রহন আমাদের নিশ্চিত করতে হবে না। যে কোন সিদ্ধান্ত গ্রহনের পূর্বে, যদি চান তাহলে আপনার আত্মীয়-স্বজন, বন্ধু অথবা আস্থাভাজন যেকারো সাথে এই ব্যাপারে আলোচনা করে নিতে পারেন। অপরপক্ষে,অংশগ্রহনকারী তথ্যপত্রটি পড়ে,যদি কোন বিষয়বস্তু বুঝতে সমস্যা হয় অথবা যদি কোন কিছু সম্পর্কে আরোবেশি জানার প্রয়োজন হয়, তবে নির্দ্বিধায় প্রশ্ন করতে পারেন।

গবেষণার প্রেক্ষাপট ও উদ্দেশ্য:

ঢাকা শহরে বসবাসকারী মেরুরুজ্জুতে আঘাত গ্রস্থ যেসকল ব্যক্তি পক্ষাঘাত গ্রস্থদের পুর্নবাসন কেন্দ্র হতে পুর্নবাসন প্রক্রিয়া সম্পন্ন করার পর, নিজ নিজ সমাজে ফিরে গিয়েছেনে এবং অন্তত পক্ষে ৬ মাস নিজ নিজ সমাজে বসবাস করেছেন, তাদেরকে এই গবেষনায় আমন্ত্রণ জানানো হবে। এর অংশ হিসেবে আপনাকেও উক্ত গবেষণা প্রকল্পে আমন্ত্রণ জানানো হলো। আপনি নিশ্চই অবগত আছেন যে, অকুপেশনাল থেরাপি চিকীৎসার মূল উদ্দেশ্য হলো, সেবাগ্রহণকারী ব্যক্তিকে তার দৈনন্দিন, সামাজিক ও পেশাগত কার্যাবলীতে যথাসম্ভব অংশ গ্রহণ করানো।পক্ষাঘাত গ্রস্থদের পুর্নবাসন কেন্দ্র হতে সেবাগ্রহণকারী মেরুরুজ্জুতে আঘাত গ্রস্থ ব্যক্তিদের চিকিৎসা ও পুনর্বাসন পরবর্তী সময়ে নিজ নিজ সমাজে তাদের সামাজিক অংশ গ্রহণ একটি গুরুত্বপূর্ণ বিষয়। যা তাদের উত্তম জীবন যাপনের ক্ষেত্রে সহায়ক ভূমিকা পালন করে। চিকিৎসা ও পুনর্বাসন পরবর্তী সময়ে মেরুরুজ্জতে আঘাত গ্রস্থ ব্যক্তি নিজ সমাজে বসবাস কালীন অবস্থায়, সামাজীক কার্যাবলীতে অংশ গ্রহণের ক্ষেত্রে কতটুকু পারদর্শী হতে পারেনতা যেমন অজানা, ঠিক তেমনি সামাজিক কার্যাবলীতে অংশ গ্রহণের ক্ষেত্রে তাদের সীমাবদ্ধতা গুলোও অজানা। গবেষণাটির সাধারণ উদ্দেশ্য হলো- ঢাকা শহরে বসবাসকারী মেরুরুজ্জুতে আঘাত গ্রস্থ মানুষের সামাজিক কার্যাবলীতে অংশ গ্রহণ এর মূল্যায়ন করা এবং এক্ষেত্রে তাদের সীমাবদ্ধতা গুলোর পরিমাপ করা।আপনার কার্যকারী অংশগ্রহণ গবেষণার উদ্দেশ্য পূরণে সহায়তা করবে বলে আমরা আশাবাদী।

এই গবেষণা কর্মটিতে অংশগ্রহনের সাথে সম্পৃক্ত বিষয়সমূহ কি সে সম্পর্কে জানা যাক।

আপনার থেকে অনুমতিপত্রে স্বাক্ষর নেবার আগে, তথ্যপত্রের মাধ্যমে গবেষনা প্রকল্পটির পরিচালনা করার তথ্যসমূহ বিস্তারিত ভাবে আপনার কাছে উপস্থাপন করা হবে। আপনি যদি এই গবেষনায় অংশগ্রহন করতে চান, তাহলে সম্মতিপত্রে আপনাকে স্বাক্ষর করতে হবে। আপনি অংশগ্রহন নিশ্চিত করলে, আপনার সংরক্ষনের জন্য সম্মতিপত্রটির একটি অনুলিপি দিয়ে দেয়া হবে। পরবর্তীতে গবেষক কর্তৃক গঠিত তথ্য-উপাত্ত সংগ্রহের একটি দলের প্রতিনিধি আপনার কাছে যাবে। আপনার থেকে চেয়ে নেওয়া যে কোন একটি নির্দিষ্ট সময়ে একটি প্রশ্নপত্রের মাধ্যমে তথ্য সংগ্রহ করা হবে।এই গবেষনার প্রকল্পে আপনার অংশগ্রহণ ঐচ্ছিক। যদি আপনি সম্মতি প্রদান না করেন তবে আপনাকে অংশগ্রহন করতে হবে না। আপনি সম্মতি প্রদান করা স্বত্তেও যে কোন সময়

গবেষককে কোন ব্যাখ্যা প্রদান করা ছাড়াই নিজের অংশগ্রহন প্রত্যাহার করতে পারবেন। গবেষনা প্রকল্পটিতে অংশগ্রহন করা কিংবা না করা অথবা পরবর্তীতে অংশগ্রহন প্রত্যাহার করার সিদ্ধান্তের সাথে আপনার পক্ষাঘাত গ্রস্থদের পুনর্বাসন কেন্দ্রে অবস্থাকালীন চিকিৎসা, চিকিৎসকদের সাথে সম্পর্ক, অকুপেশনাল থেরাপিস্টদের সাথে আপনার সম্পর্ক অথবা সিআরপির সহযোগী প্রতিষ্ঠানের সাথে সম্পর্ক কোনভাবে প্রভাবিত হবে না।

অংশগ্রহনের সুবিধা ও ঝুঁকিসমূহ কি ?

গবেষনা প্রকল্পটিতে অংশগ্রহনের জন্য আপনি সরাসরি কোন সুবিধা পাবেন না। তবে আমরা আশাবাদী যে, গবেষনার মাধ্যমে প্রাপ্ত উপাত্ত পরবর্তিতে রোগীদের চিকিৎসা কার্যক্রমকে আরো গতিশীল করতে সাহায্য করবে এবং এই গবেষণার মাধ্যমেসেবা প্রদানকারী সদস্যগণ আপনার অভিজ্ঞতার কথা জানতে পারবে এবং প্রাপ্ত তথ্য সমূহ সেবার মানবাড়াতে সাহায্য করবে।এখানে সংশ্লিষ্ট গবেষণায় অংশগ্রহনে কোন ধরনের বাড়তি ঝুঁকি, বিপত্তি অথবা অস্বস্তি নেই বলে আশা করা যাচ্ছে।

তথ্যের গোপনীয়তা কি নিশ্চিত থাকবে?

এই সম্মতিপত্রে স্বাক্ষর করার মধ্য দিয়ে, আপনি এই গবেষনা প্রকল্পে অধ্যয়নরত গবেষণা কর্মীকে আপনার ব্যক্তিগত তথ্য সংগ্রহ ও ব্যবহার করার অনুমতি দিয়েছেন। এই গবেষণা প্রকল্পের জন্য সংগৃহীত যেকোন তথ্য, যা আপনাকে সনাক্ত করতে পারে তা গোপনীয় থাকবে। আপনার সম্পর্কে সংগৃহীত তথ্যসমূহ সাংকেতিক উপায়ে উল্লেখ থাকবে। শুধুমাত্র এর সাথে সরাসরি সংশ্লিষ্ট গবেষক ও তার তত্ত্বাবধায়ক এই তথ্যসমূহে প্রবেশাধিকার পাবেন। সাংকেতিক উপায়ে চিহ্নিত উপাত্ত সমূহ পরবর্তী উপাত্ত বিশ্লেষনের কাজে ব্যবহৃত হবে।তথ্যপত্রগুলো তালাবদ্ধ ড্রয়ারে রাখা হবে। বিএইচপিআই এর অকুপেশনাল থেরাপি বিভাগে ও গবেষকের ব্যক্তিগত ল্যাপটপে উপাত্তসমূহের ইলেকট্রনিক ভার্সন সংগৃহীত থাকবে।

প্রত্যাশা করা হচ্ছে যে, এই গবেষণা প্রকল্পের ফলাফল বিভিন্ন ফোরামে প্রকাশিত এবং উপস্থাপিত হবে। যে কোন ধরনের প্রকাশনা ও উপস্থাপনার ক্ষেত্রে তথ্যসমূহ এমন ভাবে সরবরাহ করা হবে, যেন আপনার সম্মতি ছাড়া আপনাকে কোন ভাবেই সনাক্ত করা না যায়। তথ্য-উপাত্ত প্রাথমিক ভাবে কাগজপত্রে সংগ্রহ করা হবে ।

ফলাফল প্রচার সম্পর্কিত তথ্য

এই গবেষনার ফলাফল বিভিন্ন সামাজিক মাধ্যম, ওয়েবসাইট, সম্মেলন, আলোচনাসভায় এবং পর্যালোচিত জার্নালে প্রকাশ করা হবে।

অংশগ্রণকারীর পারিশ্রমিক

এই গবেষণায় অংশগ্রহনের জন্য কোন উদ্দীপনা ও পারিশ্রমিক দেবার ব্যবস্থা নেই।

গবেষণা পরিচালনার জন্য ব্যয়কৃত অর্থের উৎস

এই গবেষণাটির খরচ সম্পূর্ণ গবেষকের নিজস্ব তহবিল থেকে ব্যয় করা হবে। এই গবেষণাটি ছোট পরিসরে করা হবে এবং এখানে কোন অর্থ বহিরাগত উৎস থেকে আসবে না।

অংশগ্রহণ থেকে প্রত্যাহার সর্ম্পকিত তথ্যসমূহ

আপনি সম্মতি প্রদান করা স্বত্তেও যে কোন সময় গবেষককে কোন ব্যাখ্যা প্রদান করা ছাড়াই নিজের অংশগ্রহন প্রত্যাহার করতে পারবেন। বাতিল করার পর তথ্যসমূহ কি ব্যবহার করা যাবে কি যাবেনা তার অনুমতি অংশগ্রহণকারীর প্রত্যাহার পত্রে (শুধুমাত্র স্বেচ্ছায় প্রত্যাহারকারীর জন্য প্রযোজ্য) উল্লেখ করা থাকবে।

গবেষকের সাথে যোগাযোগের ঠিকানা

গবেষনা প্রকল্পটির বিষয়ে যোগাযোগ করতে চাইলে অথবা গবেষনা প্রকল্পটির সর্ম্পকে কোন প্রশ্ন থাকলে,এখন অথবা পরবর্তীতে যে কোন সময়ে তা জিজ্ঞাসা করা যাবে। সেক্ষেত্রে আপনি গবেষকের সাথে উল্লেখিত ০১৯২৭২২৮৬০৩ (কাজী আল-আমিন) নাম্বারে যোগাযোগ করতে পারেন।

অভিযোগ

এই গবেষনা প্রকল্প পরিচালনা প্রসঙ্গে যেকোন অভিযোগ থাকলে প্রাতিষ্ঠানিক নৈতিকতা পরিষদের সাথে এই নাম্বারে (৭৭৪৫৪৬৪-৫) যোগাযোগকরবেন।এই গবেষনা প্রকল্পটি বাংলাদেশ হেল্‌থ প্রফেশন্স ইনস্টিটিউট, সাভারের প্রাতিষ্ঠানিক নৈতিকতা পরিষদ থেকে সিআরপি-বিএইচপিআই/আইআরবি/১০/১৮/১২৩১ পর্যালোচিত ও অনুমোদিত হয়েছে।

গবেষনা থেকে নিজেকে প্রত্যাহার করা যাবে কি?

আপনি সম্মতি প্রদান করা স্বত্বেও যে কোন সময় গবেষককে কোন ব্যাখ্যা প্রদান করা ছাড়াই নিজের অংশগ্রহন প্রত্যাহার করতে পারবেন। বাতিল করার পর তথ্যসমূহ কি ব্যবহার করা যাবে কি যাবেনা তার অনুমতি অংশগ্রহণকারীর প্রত্যাহার পত্রে (শুধুমাত্র স্বেচ্ছায় প্রত্যাহারকারীর জন্য প্রযোজ্য) উল্লেখ করা থাকবে।

APPENDIX: VI

Withdrawal Form

Participants Name: …………………………………………

ID number: ………………...............

Reason of Withdraw: ……………………………………………………………………

…………………………………………………………………………………………...

Participants Name: ……………………………………

Participants Signature: ……………………………….. Day/Month/Year: …………………

APPENDIX: VII

অংশগ্রহণকারীর প্রত্যাহার পত্র

(শুধুমাত্র স্বেচ্ছায় প্রত্যাহারকারীর জন্য প্রযোজ্য)

অংশগ্রহনকারীর নামঃ ……………………………………………………………

প্রত্যাহার করার কারনঃ

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পূর্ববর্তী তথ্য ব্যবহারের অনুমতি থাকবে কিনা?

হ্যাঁ/না

অংশগ্রহনকারীর নামঃ

অংশগ্রহনকারীর স্বাক্ষরঃ **তারিখঃ**

*যদি অংশগ্রহণকারী নিরক্ষর হয়ে থাকেন, সেক্ষেত্রে-

অংশগ্রহণকারীর আঙ্গুলের ছাপ-

স্বাক্ষীর নামঃ
স্বাক্ষরঃ
তারিখঃকোড নংঃ

APPENDIX: VIII

Consent form (English)

Statement by Participants

I have been invited to participate in research titled "Evaluating social participation among people with spinal cord injury in Dhaka city". I have read the foregoing information, or it has been read to me. I have had the opportunity to ask questions about it and any questions I have been asked have been answered to my satisfaction. I consent voluntarily to be a participant in this study

Name of Participant____

Signature of Participant ____________________Date ____________________________

Statement by the researcher taking consent

I have accurately read out the information sheet to the potential participant, and to the best of my ability made sure that the participant understands that the following will be done:

1. Every information will be use in research work

2. Every information will be kept with proper confidential

3. Participants name and identity cannot be focused

I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

A copy of this participant's data collection form has been provided to the participant.

Name of Researcher taking the consent_________________________

Signature of Researcher taking the consent___________________________

Date ____________________________

APPENDIX:IX

অংশগ্রহণকারীদের সম্মতিপত্র

‘‘ঢাকা শহরে বসবাসকারী মেরুরুজ্জুতে আঘাত গ্রস্থ মানুষের সামাজিক অংশগ্রহণ এর মূল্যায়ন”- শীর্ষক গবেষনায় অংশগ্রহনের জন্য আমাকে আমন্ত্রন জানানো হয়েছে। আমি পূর্বলিখিত তথ্য পত্রটি পড়েছি বা এটা আমাকে পড়ে শোনানো হয়েছে। এই বিষয়ে আমার প্রশ্ন জিজ্ঞাসা করার সুযোগ ছিল এবং যে কোন প্রশ্নের আমি সন্তুষ্টজনক উত্তর পেয়েছি। এই গবেষনায় একজন অংশগ্রহনকারী হবার জন্য আমি স্বেচ্ছায় সম্মতি দিচ্ছি।

অংশগ্রহনকারীর নাম:
অংশগ্রহনকারীর স্বাক্ষর: তারিখ:.......................

*যদি অংশগ্রহণকারী নিরক্ষর হয়ে থাকেন, সেক্ষেত্রে-

অংশগ্রহণকারীর আঙ্গুলের ছাপ-

স্বাক্ষীর নাম:
স্বাক্ষর:
তারিখ:

গবেষক ও সম্মতিকারীর বিবৃতি:

আমি অংশগ্রহনকারীকে অংশগ্রহনকারীর তথ্যপত্রটি পড়ে শুনিয়েছি এবং আমার সর্বোচ্চ সামর্থ অনুযায়ী নিশ্চিত করেছি যে, অংশগ্রহনকারীর বোধগম্য হয়েছে যে, নিম্নোক্ত বিষয়সমূহ করা হবে।

১) সকল তথ্য গবেষণার কাজে ব্যবহৃত হবে।

২) তথ্যসমূহ সম্পূর্ণভাবে গোপনীয় করা হবে।

৩) অংশগ্রহনকারীর নাম ও পরিচয় প্রকাশ করা হবে না

আমিনিশ্চিত করেছি যে, এই বিষয় সর্ম্পকে অংশগ্রহনকারীকে প্রশ্ন জিজ্ঞাসা করার সুযোগ দেয়া হয়েছে এবং অংশগ্রহনকারী যে সকল প্রশ্ন জিজ্ঞাসাকরেছেন, আমার সর্বোচ্চ সামর্থ অনুযায়ী সেগুলোর সঠিক উত্তর প্রদান করা

সম্ভব হয়েছে। আমিনিশ্চিত করেছি যে, কোন ব্যক্তিকে সম্মতি দান করতে বাধ্য করা হয়নি। তিনি অবাধে অথবা স্বেচ্ছায় সম্মতি দিয়েছেন।

অংশগ্রহনকারীকে অংশগ্রহনকারীর তথ্য ও সম্মতিপত্রের একটি অনুলিপি দেওয়া হয়েছে।

গবেষকের নাম:

গবেষকের স্বাক্ষর: **তারিখ:**

APPENDIX: X

Questionnaire

Complete items before starting each interview			
Respondents identity number			
Interviewer identity number			
Interview date	____ Day	______ Month	____ Year
Duration of interview			
Respondent’s address			
Respondent’s mobile number			

Part one: Socio-demographic information

Sl. No.	**Questions**	**Coding categories**	**Code**
1.	How old are you?	……………Years	☐
2.	Sex	Male = 1 Female = 2	☐

Sl. No.	**Questions**	**Coding categories**	**Code**
3.	What is your educational status?	Illiterate =1 Primary pass =2 High school pass=3 SSC = 4 HSC = 5 Graduate = 6	☐
4.	What is your Marital status?	Unmarried = 1 Married = 2 Separated = 3 Divorced = 4 Widowed/Widowed = 5 Reluctant to answer = 6	☐
5.	In which type of environment/area, you live?	Rural = 1 Urban = 2 Semi-urban = 3	☐
6.	In which type of family, you live?	Joint family = 1 Single family = 2 Staying alone = 3	☐

Sl. No.	Questions	Coding categories	Code
7.	Who provides care to you at home?	Self = 1 Mother = 2 Father = 3 Brother = 4 Sister = 5 Wife = 6 Husband = 7 Siblings = 8 Relatives = 9 Others = 10	☐
8.	What was your occupation before injury?	House-wife = 1 Agriculture = 2 Govt. job = 3 Non-govt. job = 4 Self-employed (business, shop) = 5 Teacher = 6 Garment worker = 7 Day labor = 8 Student = 9 Unemployment = 10 Others,(………………)= 11	☐

Sl. No.	**Questions**	**Coding categories**	**Code**
9.	What is your current occupation?	House-wife = 1 Agriculture = 2 Govt. job = 3 Non-govt. job = 4 Self-employed (business, shop) = 5 Teacher = 6 Garment worker = 7 Day labor = 8 Student = 9 Unemployment (able to work) = 10 Unemployment (unable to work) = 11 Others,(………………)= 12	☐
10	At present, are you using any assistive device/equipment?	Yes = 1 No = 2	☐
		If yes, which one: Wheel chair = 1 Walking frame = 2 Elbow crutch = 3 Axillary crutch = 4 One stick = 5 Others,(………………)= 6	☐

Socio-economic information

Sl. No.	Questions	Coding categories	Code
1	At present, who is the main earning person of your family?	Self = 1 Mother = 2 Father = 3 Brother = 4 Sister = 5 Wife = 6 Husband = 7 Siblings = 8 Relatives = 9 Others = 10	☐
2	After rehabilitation from CRP, did you take any vocational training for income generation?	Yes = 1 No = 2	☐
		If yes, which one: Tailoring = 1 Computer training = 2 Shop management = 3 Electronics = 4 Bee keeping = 5 Animal Husbandry = 6 Mushroom farming = 7 Wood work = 8 Others,(………………)= 9	☐

Sl. No.	Questions	Coding categories	Code
3	At present, do you have any earning?	Yes = 1 No = 2 (If yes, how much? …………………………..)	☐
4	What is your source of income?	Agriculture = 1 Govt. job = 2 Non-govt. job = 3 Self-employed (business, shop) = 4 Teacher = 5 Garment worker =6 Day labor = 7 Others,(………………)= 8	☐
5	What is your main role in your family?	Mother = 1 Father = 2 Brother = 3 Sister = 4 Wife = 5 Husband = 6 Siblings = 7 Others,(………………)= 8	☐

Part two: Injury related information

Sl. No.	Questions	Coding categories	Code
1.	What is the diagnosis of your injury?	Traumatic Tetraplegia = 1 Traumatic Paraplegia = 2 Non-traumatic tetraplegia = 3 Non-traumaticparaplegia = 4	☐
2.	Living experience in own community, after completing rehabilitation	……………………………years	☐
3.	What is the cause of injury	Road accident = 1 Fall from height = 2 Violence = 3 During play = 4 Diving = 5 Others = 6	☐

Sl. No.	Questions	Coding categories	Code
4.	At present, do you have any secondary/injury related complications?	Yes = 1 No = 2	☐
		If yes, which one: Pain = 1 Pressure sore = 2 UTI = 3 Muscle spasticity = 4 Muscle contracture = 5 Burning sensation = 6 Others (…………………) = 7	☐

Participation scale version 6.0

No	Participation Scale	Not specified, not answered	Yes	Sometimes	No	Irrelevant, I don't want to, don't haveto	NO problem	Small	Medium	Large	SCORE
1	Do you have equal opportunity as your peers to find work?		0			0					
	[if sometimes or no] How big a problem is it to you?						1	2	3	5	
2	Do you work as hard as your peers do? (same hours, type of work etc)		0			0					
	[if sometimes or no] How big a problem is it to you?						1	2	3	5	
3	Do you contribute to the household economically in a similar way to your peers?		0			0					
	[if sometimes or no] How big a problem is it to you?						1	2	3	5	
4	Do you make visits outside your village / neighborhood as much as your peers do? (except for treatment) e.g. bazaars, markets		0			0					
	[if sometimes or no] How big a problem is it to you?						1	2	3	5	
5	Do you take part in major festivals and rituals as your peers do? (e.g. weddings, funerals, religious festivals)		0			0					
	[if sometimes or no] How big a problem is it to you?						1	2	3	5	
6	Do you take as much part in casual recreational/social activities as do your peers? (e.g. sports, chat, meetings)		0			0					
	[if sometimes or no] How big a problem is it to you?						1	2	3	5	
7	Are you as socially active as your peers are? (e.g. in religious/community affairs)		0			0					
	[if sometimes or no] How big a problem is it to you?						1	2	3	5	
8	Do you have the same respect in the community as your peers?		0			0					
	[if sometimes or no] How big a problem is it to you?						1	2	3	5	
9	Do you have opportunity to take care of yourself (appearance, nutrition, health, etc.) as well as your peers?		0			0					
	[if sometimes or no] How big a problem is it to you?						1	2	3	5	
10	Do you have the same opportunities as your peers to start or maintain a long-term relationship with a life partner?		0			0					
	[if sometimes or no] How big a problem is it to you?						1	2	3	5	
11	Do you visit other people in the community as often as other people do?		0			0					
	[if sometimes or no] How big a problem is it for you?						1	2	3	5	

No	Participation Scale	Not specified,	Yes	Sometimes	No	Irrelevant, I don't want to, don't haveto	No problem	Small	Medium	Large	SCORE
12	Do you move around inside and outside the house and around the village / neighbourhood just as other people do?		0			0					
	[if sometimes or no] How big a problem is it to you?						1	2	3	5	
13	In your village / neighbourhood, do you visit public places as often as other people do? (e.g. schools, shops, offices, market and tea/coffee shops)		0			0					
	[if sometimes or no] How big a problem is it to you?						1	2	3	5	
14	In your home, do you do household work?		0			0					
	[if sometimes or no] How big a problem is it to you?						1	2	3	5	
15	In family discussions, does your opinion count?		0			0					
	[if sometimes or no] How big a problem is it to you?						1	2	3	5	
16	Do you help other people (e.g. neighbours, friends or relatives)?		0			0					
	[if sometimes or no] How big a problem is it to you?						1	2	3	5	
17	Are you comfortable meeting new people?		0			0					
	[if sometimes or no] How big a problem is it to you?						1	2	3	5	
18	Do you feel confident to try to learn new things?		0			0					
	[if sometimes or no] How big a problem is it to you?						1	2	3	5	

Comment: Total score :

Name:____

Age:_____ Gender:________

Interviewer:_____________________________________ Dateofinterview:_____/____/_____

Grades of participation restriction

No significant restriction	Mild restriction	Moderate restriction	Severe restriction	Extreme restriction
0 – 12	13 – 22	23 – 32	33 – 52	53 – 90

Disclaimer: The Participation Scale is the intellectual property of the Participation Scale Development Team. Neither the Team or its sponsors can be held responsible for any consequences of the use of the Participation Scale.

APPENDIX: XI

প্রশ্নাবলী (বাংলা)

প্রতিটি সাক্ষাৎকার শুরু করার আগে নিচের প্রদত্ত অংশগুলো পূরণ করে নিন			
উত্তরদাতার সনাক্তকরণ নম্বরঃ			
সাক্ষাৎকার গ্রহণকারীর সনাক্তকরণ নম্বরঃ			
সাক্ষাৎকার গ্রহণের তারিখঃ	দিন	মাস	বছর
সাক্ষাৎকারের সময় কালঃ			
উত্তরদাতার ঠিকানাঃ			
উত্তরদাতার মোবাইল নম্বরঃ			

অংশ-১

(জনসংখ্যাতাত্ত্বিক তথ্যাবলী)

সিরিয়াল নম্বর	প্রশ্নসমূহ	কোডিং বিভাগ	কোড
১	আপনার বয়স কত?	............বছর	☐
২	লিঙ্গ	পুরুষ =১ মহিলা =২	☐
৩	আপনার শিক্ষাগত যোগ্যতা কি?	অশিক্ষিত =১ প্রাথমিক শিক্ষা =২ হাই স্কুল = ৩ মাধ্যমিক = ৪ উচ্চ মাধ্যমিক = ৫ স্নাতক = ৬	☐
৪	আপনার বৈবাহিক অবস্থা কি?	অবিবাহিত =১ বিবাহিত = ২ আলাদা থাকেন = ৩ তালাক প্রাপ্ত = ৪ বিধবা = ৫ উত্তর দিতে অনিচ্ছুক = ৬	☐

সিরিয়াল নম্বর	প্রশ্নসমূহ	কোডিং বিভাগ	কোড
৫	আপনি কোন ধরনের পরিবেশে/এলাকায় বসবাস করেন?	গ্রামীন = ১ শহুরে = ২ আধা-শহুরে = ৩	☐
৬	আপনি কোন ধরনের পরিবারে বসবাস করেন?	যৌথ পরিবার = ১ একক পরিবার = ২ একা থাকেন = ৩	☐
৭	বাড়িতে কে আপনার যত্ন নিয়ে থাকেন?	নিজে = ১ মা = ২ বাবা = ৩ ভাই = ৪ বোন = ৫ স্ত্রী = ৬ স্বামী = ৭ সন্তান-সন্ততি = ৮ আত্মীয়-স্বজন = ৯ অন্যান্য,(................) = ১০	☐
৮	আঘাত পাওয়ার পূর্বে আপনার পেশা কি ছিলো?	গৃহিনী = ১ কৃষিকাজ = ২ সরকারী চাকুরিজীবি = ৩ বেসরকারী চাকুরিজীবি = ৪ আত্মকর্ম সংস্থান (ব্যবসা, দোকান) = ৫ শিক্ষকতা = ৬ গ্রার্মেন্ট শ্রমিক = ৭ দিন মজুর = ৮ শিক্ষার্থী = ৯ বেকার = ১০ অন্যান্য, (...........) =১১	☐

সিরিয়াল নম্বর	প্রশ্নসমূহ	কোডিং বিভাগ	কোড
৯	আপনার বর্তমান পেশা কি?	গৃহিনী = ১ কৃষিকাজ = ২ সরকারী চাকুরিজীবি = ৩ বেসরকারী চাকুরিজীবি = ৪ আত্মকর্ম সংস্থান (ব্যবসা, দোকান) = ৫ শিক্ষকতা = ৬ গ্রার্মেন্ট শ্রমিক = ৭ দিন মজুর = ৮ শিক্ষার্থী = ৯ বেকার (কাজে সক্ষম ব্যক্তি) = ১০ বেকার (কাজে অক্ষম ব্যক্তি) = ১১ অন্যান্য,(............) = ১২	☐
১০	বর্তমানে আপনি কি কোনো সহায়ক উপকরন ব্যবহার করছেন?	হ্যাঁ = ১ না = ২	☐
		যদি হ্যাঁ হয়, তাহলে কোনটি: হুইল চেয়ার = ১ ওয়াকিং ফেম = ২ এক্সিলারি ক্রাচ = ৩ এলবো ক্রাচ = ৪ সহায়ক লাঠি = ৫ অন্যান্য (..............) = ৬	☐

সামাজিক-অর্থনৈতিক তথ্যাবলি

সিরিয়াল নম্বর	প্রশ্নসমূহ	কোডিং বিভাগ	কোড
১	বর্তমানে, আপনার পরিবারে প্রধান উপার্জনক্ষম ব্যক্তি কে?	নিজে = ১ মা = ২ বাবা = ৩ ভাই = ৪ বোন = ৫ স্ত্রী = ৬ স্বামী = ৭ সন্তান-সন্ততি = ৮ আত্মীয়-স্বজন = ৯ অন্যান্য,(..........) = ১০	☐
২	সি.আর.পি. থেকে পূনর্বাসনের পর আপনি উপার্জন বৃদ্ধির জন্য কোন ভোকেশনাল প্রশিক্ষণ নিয়েছিলেন কি না?	হ্যাঁ = ১ না = ২	☐
		যদি হ্যাঁ হয়, তাহলে কোনটি: দর্জির কাজ = ১ কম্পিউটার প্রশিক্ষণ = ২ দোকান পরিচালনা = ৩ ইলেকট্রনিক্স প্রশিক্ষণ = ৪ মৌমাছি চাষ = ৫ পশু পালন = ৬ মাশরুম চাষ = ৭ কাঠের কাজ = ৮ অন্যান্য,(...........) = ৯	☐

সিরিয়াল নম্বর	প্রশ্নসমূহ	কোডিং বিভাগ	কোড
৩	বর্তমানে আপনার কোন উপার্জন আছে কি?	হ্যাঁ = ১ না = ২ (যদি হ্যাঁ হয়, তাহলে কত টাকা? ....)	☐
৪	আপনার আয়ের উৎস কি?	কৃষিকাজ = ১ সরকারী চাকুরি = ২ বেসরকারী চাকুরি = ৩ আত্মকর্ম সংস্থান (ব্যবসা, দোকান) = ৪ শিক্ষকতা = ৫ গ্রার্মেন্ট শ্রমিক = ৬ দিন মজুরী = ৭ অন্যান্য,(...........) = ৮	☐
৫	পরিবারে আপনার প্রধান ভুমিকা কি?	মা = ১ বাবা = ২ ভাই = ৩ বোন = ৪ স্ত্রী = ৫ স্বামী = ৬ সন্তান-সন্ততি = ৭ অন্যান্য,(...........) = ৮	☐

অংশ-২

(আঘাত জনিত তথ্যাবলি)

সিরিয়াল নম্বর	প্রশ্নসমূহ	কোডিং বিভাগ	কোড
১	আপনার আঘাতের নির্ণয় কি?	ট্রমাটিক টেট্রাপ্লেজিয়া = ১ ট্রমাটিক প্যারাপ্লেজিয়া = ২ নন– ট্রমাটিক টেট্রাপ্লেজিয়া= ৩ নন– ট্রমাটিক প্যারাপ্লেজিয়া= ৪	☐
২	পুনর্বাসনের পর নিজ সমাজে বসবাসের অভিজ্ঞতা	………………… বছর	☐
৩	আঘাতের কারন	সড়ক দুর্ঘটনা= ১ উচু স্থান থেকে পড়ে যাওয়া = ২ হিংস্রতা = ৩ খেলার সময় = ৪ ডাইভিং = ৫ অন্যান্য = ৬	☐

সিরিয়াল নম্বর	প্রশ্নসমূহ	কোডিং বিভাগ	কোড
৪	বর্তমানে আপনার আঘাত জনিত কোন জটিলতা আছে কি না?	হ্যাঁ = ১ না = ২	☐
		যদি হ্যাঁ হয় তাহলে কোনটি: ব্যথা = ১ চাপজনিত ঘা = ২ ইউ.টি.আই. = ৩ মাংস পেশির জড়তা = ৪ মাংস পেশির সংকোচনশীলতা = ৫ জালাপোড়া = ৬ অন্যান্য (.................) = ৭	☐

PARTICIPATION-SCALE

সমকক্ষ ব্যক্তি সম্পর্কে অংশগ্রহণকারীকে ধরনা প্রদানঃ Explain the concept of “peers” to the participant .

সাক্ষাৎকার গ্রহণকারী নিজেই “Peers” (পিয়ার’স) সম্পর্কে বুঝা এবং উত্তরদাতাকে কি ভাবে ব্যাখ্যা করবে তা খুবই গুরুত্বপূর্ণ। উত্তরদাতাকে পরিষ্কার করে বুঝাতে হবে নির্দিষ্ট প্রশ্নের ক্ষেত্রে কে তার পিয়ার বা সমকক্ষ ব্যক্তি। সমকক্ষ ব্যক্তি বলতে রোগ বা বিকালাঙ্গতা ব্যতীত সকল ক্ষেত্রে উত্তরদাতার মত একই পর্যায়ের (ভৌগলিক, সামাজিক, সাংস্কৃতিক, অর্থনৈতিক ক্ষেত্রে) ব্যক্তিকে বুঝায়। উত্তরদাতাকে জিজ্ঞাসা করতে হবে, সে তার সমকক্ষ ব্যক্তির মত অংশ গ্রহণ করতে পারে কি না। যদি প্রশ্নটি তার বয়স, লিংগ, পেশা, সমাজে অবস্থান সম্পর্কিত হয়, তা হলে তখন তার পিয়ার হবে তার সমবয়সী, সমলিংগ, সমপেশার অন্যান্য ব্যক্তি। যদি উত্তরদাতা মেরুরুজ্জতে আঘাতগ্রস্থ একজন ব্যক্তি হয়, তখন পিয়ার হবে ঐ এলাকার। সমাজে তার বয়সীর ব্যক্তি যাদের মেরুরুজ্জতে আঘাতজনিত রোগ নাই। উত্তরদাতা যেন তার অবস্থার সহিত তার পিয়ার বা সমকক্ষ ব্যক্তির অবস্থার তুলনা করে এটা সব সময় মনে করিয়ে দেওয়া খুবই গুরুত্বপূর্ণ। প্রশ্ন করার সময় উত্তরদাতাকে জিজ্ঞাসা করতে হবে যে, সে যেন একজন নির্দিষ্ট ব্যক্তিকে চিন্তা করে (উদাহরণ স্বরূপ সহকর্মী, ভাই, বোন, এলাকার কোন ব্যক্তি)

Peers are those who are similar to the respondent in all respects (socio-cultural, economic and demographic) except for the disease or disability. The respondent is asked whether (s)he is restricted in participation in comparison to his or her peers. If a question refers to age, sex, occupation, position in the family or community, then peers would be those of similar age, sex, occupation etc. If a young person suffering from Spinal Cord Injury (SCI) is a respondent, then his/her peer would be a young person in his/her community not suffering from Spinal Cord Injury (SCI). It is necessary to keep reminding the respondent to compare his or her situation with that of their peers. Ask the patient to think of a particular person (e.g. colleague, brother, sister, someone from the community) during the questions.

Sl. No.	**অংশগ্রহনমূলক মাত্রা** **Participation-scale**	সুনির্দিষ্ট নয়/ জবাব নেই	হ্যাঁ Yes	মাঝে মাঝে Sometimes	না No	অপ্রাসঙ্গিক, Irrelevant	সমস্যা নেই No problem	অল্প Small	মাঝারী Medium	গুরুতর Large	স্কোর Score
			0			0	1	2	3	5	
1	আপনার সমকক্ষদের যেভাবে কাজ খোঁজার/পাওয়ার সুযোগ আছে আপনারও সেভাবে আছে কি? Do you have equal opportunity as your peers to find work?		0			0					
	এটি আপনার ক্ষেত্রে কত বড় সমস্যা? [If sometimes, no or irrelevant] how big a problem is it to you?						1	2	3	5	
2	আপনি কি আপনার সমকক্ষদের মতো কঠোর পরিশ্রম করেন? (একই রকম সময়/শ্রমঘন্টা কাজের ধরন ইত্যাদি) Do you work as hard as your peers do? (same		0			0					

	hours, type of work etc)										
	এটি আপনার ক্ষেত্রে কত বড় সমস্যা? [If sometimes, no or irrelevant] how big a problem is it to you?						1	2	3	5	
3	আপনি কি পারিবারিক কাজে আপনার সমকক্ষদের মতো পরিবারে টাকা পয়সা দিয়ে সহযোগিতা করেন? Do you contribute to the household economically in a similar way to your peers?		0			0					
	এটি আপনার ক্ষেত্রে কত বড় সমস্যা? [If sometimes, no or irrelevant] how big a problem is it to you?						1	2	3	5	

4	আপনি কি আপনার সমকক্ষদের মতো গ্রামের বাইরে বেড়াতে যান? (চিকিৎসা ছাড়া) উদাহরণস্বরুপ বাজার, মেলা, নিকটবর্তী গ্রামে। Do you make visits (travel) outside your village/neighborhood as much as your peers do? (except for treatment) e.g. Bazaars, markets, nearby villages .		0			0					
	এটি আপনার ক্ষেত্রে কত বড় সমস্যা? [If sometimes, no or irrelevant] how big a problem is it to you?						1	2	3	5	
5	আপনি কি বড় বড় উৎসবে এবং ধর্মীয় অনুষ্ঠানে যোগদান করেন, যেখানে সবাই যোগদান করেন? (উদাহরণ স্বরুপ বিবাহ, অন্ত্যেষ্টিক্রিয়া, ধর্মীয় অনুষ্ঠান) Do you take part in major festivals and rituals as your peers do? (e.g. wedding, funerals, religious festivals)		0			0					
	এটি আপনার ক্ষেত্রে কত বড় সমস্যা? [If sometimes, no or irrelevant] how big a problem is it to you?						1	2	3	5	
6	আপনি কি আপনর সমকক্ষদের মতো পাড়ায় বিভিন্ন অনুষ্ঠানে ও সামাজিক কাজে আপনার যতটুকু সম্ভব অংশ গ্রহন করেন? (উদাহরণস্বরুপ খেলাধূলা, খোশগল্প করা, আলোচনা সভা) Do you take as much part in casual recreational/social activities as do your peers? (e.g. sports, chat, meetings)		0			0					

	এটি আপনার ক্ষেত্রে কত বড় সমস্যা? [If sometimes, no or irrelevant] how big a problem is it to you?						1	2	3	5	
7	আপনি কি আপনার সমকক্ষদের মতো সামাজিক কর্মকান্ডে সক্রিয়? (উদাহরণ স্বরূপ ধর্মীয় ও মহল্লার সামাজিক কাজে) Are you as socially active as your peers are (e.g. in religious/community affairs)		0			0					
	এটি আপনার ক্ষেত্রে কত বড় সমস্যা? [If sometimes, no or irrelevant] how big a problem is it to you?						1	2	3	5	
8	এলাকায় আপনার সমকক্ষদের মতো আপনিও কি একই রকম সম্মান পান? Do you have the same respect in the community as your peers?		0			0					
	এটি আপনার ক্ষেত্রে কত বড় সমস্যা? [If sometimes, no or irrelevant] how big a problem is it to you?						1	2	3	5	
9	আপনার কি সমকক্ষদের মতো নিজের যত্ন নেওয়ার সুযোগ আছে (উদাহরণ স্বরূপ চেহারা, পুষ্টি, স্বাস্থ্য ইত্যাদি) Do you have opportunity to take care of yourself (appearance, nutrition, health, etc.) as well as your peers?		0			0					
	এটি আপনার ক্ষেত্রে কত বড় সমস্যা? [If sometimes, no or irrelevant] how big a problem is it to you?						1	2	3	5	
10	আপনার কি সমকক্ষদের মতো জীবন সঙ্গীর সাথে দীর্ঘমেয়াদী সম্পর্ক শুরু/বজায় রাখার সুযোগ আছে? Do you have the same opportunities as your peers to start or maintain a long-term relationship with a life partner?		0			0					
	এটি আপনার ক্ষেত্রে কত বড় সমস্যা? [If sometimes, no or irrelevant] how big a problem is it to you?						1	2	3	5	
11	আপনি কি অন্যদের মতো এলাকার লোকদের বাড়ীতে প্রায় বেড়াতে যান? Do you visit other people in the community as often as other people do?		0			0					
	এটি আপনার ক্ষেত্রে কত বড় সমস্যা? [If sometimes, no or irrelevant] how big a problem is it to you?						1	2	3	5	
12	আপনি কি অন্যদের মতো বাড়ির ভিতরে, বাইরে এবং গ্রামের সবদিকে বা প্রতিবেশীদের		0			0					

	বাড়িতে চলাফেরা করেন? Do you move around inside and outside the house and around the village/neighborhood just as other people do?										
	এটি আপনার ক্ষেত্রে কত বড় সমস্যা? [If sometimes, no or irrelevant] how big a problem is it to you?						1	2	3	5	

13	আপনার গ্রামে বা এলাকায় যেখানে অনেক লোকের সমাগম সেখানে আপনি কি যান? (উদাহরণ স্বরুপ বিদ্যালয়, দোকান পাঠ, কার্যালয়, বাজার, চা/কফির দোকান) In your village/neighborhood, do you visit public place as often as other people do? (e.g. school, shop, offices, market and tea/coffee shops)		0			0					
	এটি আপনার ক্ষেত্রে কত বড় সমস্যা? [If sometimes, no or irrelevant] how big a problem is it to you?						1	2	3	5	
14	আপনি কি বাড়িতে পারিবারিক/গৃহস্থালী কাজ করেন? In your home, do you do household work?		0			0					
	এটি আপনার ক্ষেত্রে কত বড় সমস্যা? [If sometimes, no or irrelevant] how big a problem is it to you?						1	2	3	5	
15	পারিবারিক আলোচনায় আপনার মতামাতের গুরুত্ব দেয় কি? In family discussions, does your opinion count?		0			0					
	এটি আপনার ক্ষেত্রে কত বড় সমস্যা? [If sometimes, no or irrelevant] how big a problem is it to you?						1	2	3	5	
16	আপনি কি অন্যদের সাহায্য করেন? (উদাহরণ স্বরুপ প্রতিবেশী, বন্ধু বান্ধব অথবা আত্মীয় স্বজন) Do you help other people (e.g. neighbors, friends		0			0					

	or relatives)?										
	এটি আপনার ক্ষেত্রে কত বড় সমস্যা? [If sometimes, no or irrelevant] how big a problem is it to you?						1	2	3	5	
17	অচেনা লোকদের সাথে দেখা হলে কথা বলতে আপনি কি স্বাচ্ছন্দ্য বোধ করেন? As you comfortable meeting new people?		0			0					
	এটি আপনার ক্ষেত্রে কত বড় সমস্যা? [If sometimes, no or irrelevant] how big a problem is it to you?						1	2	3	5	
18	আপনি কি আত্মবিশ্বাসের সাথে নতুন কোন কিছু শিখতে চেষ্টা করেন? Do you feel confident to try to learn new things?		0			0					
	এটি আপনার ক্ষেত্রে কত বড় সমস্যা? [If sometimes, no or irrelevant] how big a problem is it to you?						1	2	3	5	

মন্তব্যঃ

Total score:

উত্তরদাতার নামঃ

বয়সঃ **লিঙ্গঃ**

সাক্ষৎকার গ্রহনকারীঃ **সাক্ষাৎকার গ্রহনের তারিখঃ**

No significant restriction	Mild restriction	Moderate restriction	Severe restriction	Extreme restriction
0 – 12	13 – 22	23 – 32	33 – 52	53 – 90

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