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**“School life participation and barriers of the student with spinal cord Injury
after completion of rehabilitation service from CRP”**

By

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ABSTRACT

Spinal cord injury is one of the devastating and disabling coding for early childhood and adolescent but its impact on school participation is not well understood at country perspective. Participation in school plays very important roles to build-up identity, independency, skill development, satisfaction, well-being and improving quality of life for who have early onset of spinal cord injured. This study aimed to address school participation and barrier of student with spinal cord injury. A cross-sectional study was carried out with purposive convenient sampling design to identify 53 potential participants between February and April, 2018. Result foud that most of the participant (88.6%) in terms of participation in educational activitis have some sorts of problem. Using educational material for school activity also reported as a big problem (96.2%). Among them majority have (96.2%) problem to participate in social play and recreational activities, race, leisure, art, sports with others at school. Where participants were least restricted (37.7%) in communication with their pears, teacher and others at school. Though they less restricted in communication with others but only 7.5% are allays able to move around the school and access toilet as well as water fountain. There is a moderate inverse correlation between the school life participation and the environmental barrier, $r_s = -0.527$ ($p < 0.001$), that indicate the greater level of participation happened within fewer environment related problem. Comparison of participation between the group paraplegia and tetrapegia indicate that mean Rank of paraplegia (32.50) and tetraplegia (24.832) this indicates that school participation of paraplegic group is higher than the tetalpegic group.

Keywords: Spinal cord injury, participation, Barrier

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ABBREVIATIONS

ASIA- American Spinal Injury Association
ADLs- Activity of Daily Livings
BHPI- Bangladesh Health Professions Institute
CI- Confidence Interval
CBR- Community Based Rehabilitation
CRP- Centre for the Rehabilitation of the Paralysed
FFH- Fall from Height
IRB- Institutional Review Board
ICF- International Classification of Functioning
MVA- Motor Vehicle Accident
NGO- Non Governmental Organization
QOL- Quality of Life
RTA- Road Traffic Accident
SCI-Spinal Cord Injury
SD- Slandered Deviation
SPSS-Statistical Package for the Social Science
WHO- World Health Organization

1.1 Background of Study

Spinal Cord Injuries (SCI) are traumatic experiences and can sudden change the life of the individuals who sustained the injury. The annual incidence of SCI is approximately 40 cases per million populations in the U.S. Among this population, 16.1% are reported being students (NSCISA 2015). Spinal Cord Injury often leads to permanent neurological damage and range of associated consequence such as paralysis, loss of sensation, bowel bladder function impairment and loss of functional activity such as ADLs, employment, and Schooling (Hervey, 2008). Furthermore following an SCI, the ability to participate in meaningful life roles and activities outside the home can change and diminish (Brown, Gordon, Spielman & Haddad, 2002; Whiteneck et al., 2004). Participation in work, school, leisure and sporting activities greatly decreases (Tasiemski, Bergstrom, Savic & Gardner, 2000), with an accompanying increase in time spent on individual home based occupations such as watching television, listening to the radio, and reading (Barclay et al., 2011), potentially leading to social isolation (Brown et al., 2002). A major factor contributing to leading a 'good life' following an acquired disability is establishing and maintaining close relationships (Dunn & Brody, 2008). Many meaningful connections are made through participation in activities outside the home, such as working or studying, being involved in peers, sporting groups, leisure activities, going to the local shops. Social and community participation is now recognized as an important goal and outcome of rehabilitation of people with an SCI (Carpenter, Forwell, Jongbloed & Backman, 2007; Schonherr, Groothoff, Mulder & Eisma, 2005; WHO, 2001). Returning to school constitutes as a challenge that involves a greater degree of adaptation including but not limited to physical, emotional, social and learning. Existing literature on difficulties faced by people with SCI after returning to school shows dissatisfaction of disabled students

who studied at various educational institutes (Hemmingsson and Borell 2002). Contemporary occupational therapy literature shows evidence regarding the participation of pupils with physical limitations at school, which reports students restricted participation in specific school activities and settings (Egilson 2005, Schenker et al 2005, 2006). The barriers identified by research show physical inaccessibility, the lack of knowledge on adaption of the curriculum, the lack of knowledge on adapted instructional methods, limited adaptive equipment and inadequate collaboration between support services and schools Case-Smith and Rogers (2005), Egilson 2005, Hemmingsson et al 2007. The rehabilitation literature has provided information about student school performance after SCI, a study, conducted by Andrews and Jung (1979) showed that only 1 of the 4 children over the age of 1 year old remained in school beyond 9th grade. In another study, Graham, Weingarden, and Murphy (1991) identified students aged 12 to 19 years who returned to educational settings after a SCI, 1 subsequently died, 3 of the student dropped out of school, 2 remained on their degree programs, and 7 continued in school or advanced onto postsecondary education.

Mulcahey (1992) used a phenomenological approach to conduct longitudinal interviews with 4 teenagers who had sustained a SCI within the previous 2 years and had returned to school for a minimum of 3 months. From the interviews Mulcahey (1992) found educational participation is limited by barriers such as wheelchair accessibility and transportation problems, difficulty completing certain types of school work, teachers and parents attitudes, and reluctance to ask for assistance. Emerging themes identified were role change, people's interactions, feelings, coping strategies, accessibility, and self-image. The adolescents in the Mulcahey (1992) study experienced difficulty because both themselves and the environment to which they returned. Mulcahey (1992) noted the existence of a "major gap between the rehabilitation world and authentic environments"(p.311) to which these students with SCI returned. Participation in

Occupation is essential in development of a healthy identity and become active & independent member of the society.

1.1. Justification of the study

Disability is a major concern issue in Bangladesh as well as all over the world (Alam, 2009). Worldwide over a billion people are estimated to live with some form of disability. According to the report of World Health Organization, about 15% of the world's population is disabled due to a range of cause. In Bangladesh, the estimated number of persons with disabilities is around 140 million people that mean over 10% of its total population (Faruque, 2008). Furthermore, the rates of disability are increasing day by day due to increase in chronic health conditions. Rights of persons with disabilities, is one of the least understood, or rather, one of the most misunderstood issues in Bangladesh. In the recent time, Government organization are highly concerned and deliberately promoting rights of the person with disability through implementing components of the United Nations Convention on the Rights of the Persons with Disabilities, amended in 2013. The success of the convention is highly depend on service based program rather than charity through promoting knowledge, attitude and practices of the whole country including government, non-government organization, parents and the community people.

Every year CRP completed rehabilitation program approximately 400 patients. According to CRP data base, CRP had admitted patients (from July 2014 to June 2015) among them 300 patients were discharged with completing their full rehabilitation program. Within these 300 patients 25 patients was found as a student of different class. Rehabilitation program highly focused on combination of educational and intervention program regarding physical, psychological, social and cultural aspects rather than only focused on intervention based program. For student they use counseling, writing practice, direct school engagement by Occupational Therapist. It is found in literature that educational achievement is an important factor in determining employment after Spinal cord injury. In a study of 362 sample with spinal Cord injuries, (Krause and Anderson 2008) found

that employment rates ranged from 9% for those with less than a high school education to 52% for those with 16 or more years of education (Massagali and colleagues 2011). In this group, the current employment rate was 0% for those with 12 years or less of education versus 71% for those with a college degree. Many studies have shown a strong correlation between higher levels of education and increased rates of employment. During CRP follow-up program it is often found that dropout from study is very common phenomena for student with SCI after returning to their community. Thus, returning to school is an important goal in the process rehabilitation of the young person with SCI. Through conducting literature search by manual and online source, it was found that there have conducted numerous studies on spinal cord injury. Most of these studies are related with Demography, prevalence, pathogenesis, cause, medical and therapeutic intervention on Spinal cord injury. It is the analysis of Law et al. (2004), beside of the occupational therapist all other pediatric rehabilitation practitioners recognize that personal and environmental factors both are influenced in any successful participation. There is also a lack of information regarding what person and environmental characteristics that are related to participation. No evidence was found to find out school life participation of SCI. There was a gap in knowledge. Therefore, the investigator was interested to know

1.3 Research Question

What are the School life participation and barriers for the student with spinal cord Injury after completion of rehabilitation service from CRP?

1.4 Operational Definition

Spinal Cord Injury (SCI): The term spinal cord injury refers to neurological damage of the spinal cord following trauma. SCI can be due to both traumatic and non traumatic causes. It causes paralysis to all four limbs called tetraplegia or only lower limbs, hips and trunk which is called paraplegia depending on the level of injury. Sometimes there might be some upper limb function in tetraplegia .SCI can be occurred in different region of the spinal cord. Age rang for occurrence of spinal Cord injury most often middle age. Injury to different area of the spine gives different picture of the physical and functional limitation in patients.

Rehabilitation: of people with disability is a process aimed at enabling them to reach maintain their optimal level of physical, Psychological and social function. Rehabilitation provides disable people with the tools they need to achieve independence and self determination.

Barrier: Barrier is the element of human life which restricts individual function; there is several kind of barrier. Environmental, physical, social, cultural, personal. For Spinal Cord Injury adolescents reintegration to the community there are some common barrier such as ,Physical, lack of mobility device , Environmental, attitudinal, Social,

Schooling: Schooling is the meaningful occupation for young adult life. Schooling determines the future carrier plan and independent earning. It gives opportunities for learning for future life. Schooling opportunity for people with disability very few in Bangladesh. And it is more difficult for spinal Cord injury younger group in their community. Though Govt. have low for inclusive education.

Participation: Participation defines as “involvement in life situations,” (World Health Organization, 2007). Research focused participation as the engagement of SCI in home, school and community activities to develop identity, independency, skills, well-being and improving the quality of life.

This chapter reviewed literature related to the research topic under the following sub-headings; Spinal cord injury, concept of participation, impact of cerebral palsy in participation, Schooling barriers.

2.1. Spinal Cord Injury

Spinal Cord Injury (SCI), a shocking experience to an individual all over the world. Nearly 20,000 new cases of SCI are added every year. Augutis (2007) responded that around 120 persons stand SCI each year. The prevalence of SCI is different in case of economic, social, political and cultural structure of each region. In developed countries, incidence rate of SCI varies from 12.1 to 57.8 cases per million populations. In developing countries, Incidence rate of SCI varies from 12.7 to 29.7. In US, the annual incidence of SCI is about 40 cases per million populations (Yousef zadeh-Chabok *et al.*, 2015). It has been suggested by (Smith, Purzner and Fehlings, 2010) the incidence and prevalence of SCI in the geriatric population (>65 years of age) are growing. In Iran, most vulnerable cause of SCI is motor vehicle accident, violence and falling in the elder persons. The most SCI cases are young men in age range between 21 to 30 years old (Yousef zadeh-Chabok *et al.*, 2015). In UAE, it was conducted a research study of 239 patients, among them 90% were males and 84% were in the productive years of 25–54. Among 84%, majority were from the Indian subcontinent 56%. Road was the most common location for spinal injury (47%) followed by work (39%). On the other hand, another study consists of 239 patients, 215 males (90%) (Male: Female ratio was 9:1). The mean age of patient was 37.5 years. This is similar to other countries such as, Italy, United States and Pakistan but lower than Japan and China. Fall from height is the most common cause of spine injury in developing countries (Adam and Stein, 2015). Fall from height is the leading cause which include fall from ladder, tree, height and cliff (Shrestha,

Shrestha and Shrestha, 2013) and road traffic accident is another important cause of SCI (Yang *et al.*, 2014). Yousefzadeh-Chabok *et al.* (2015) conducted a descriptive study among 76 patients; the male and female ratio was 7.4:1. 80% of them were under 45 years. Motor vehicle accident (48.7%) and falling (42.1%) are the most leading cause of SCI. Men are more at risk of SCI due to MVA whereas victims are source of income in family and human resource in society. Singh *et al.* (2003) suggest that the occurrence of SCI can differ in race. Since 2010, SCI rate of White: 67.0%, African American: 24%, Hispanic-Latino: 10% and Asian: 2%. In Bangladesh, an observational study was carried on 84 males with SCI due to fall while carrying heavy load on head. 95% of them were 40 years or less. 94% patients were farmers and laborers and the rest (6%) were students and service holders and none of them was regular load carrier (Hoque *et al.*, 2012). Another study conducted by Razzak, Helal and Nuri (2011) the mean life expectancy was established to be 5.36 years. 56.4% of persons with SCI died within 5 years and 43.6% survived 5 years or more after injury. It was reported that life expectancy of the general population was 10-12 times greater than for the SCI population.

2.2 Concept of Participation

The ICF is an interactive health model that illustrates a complex relationship between health conditions, body function and structure, activities, participation, contextual factors environmental factors and personal factors (World Health Organization, 2001) (Figure 2.2.1).

There are mainly two parts for describing the ICF, the first part deals with the functioning and disability while second part deals with contextual factors (World Health Organization, 2001). Functioning and disability has two components body functions and structures; activities and participation (World Health Organization, 2001). In the ICF,

‘functioning’ is used as an umbrella term to encompass body functions, activities and participation (World Health Organization, 2001). In contrast, ‘disability’ is used as the umbrella term for impairments, activity limitations and participation restrictions (World Health Organization, 2001). The contextual factors include the complete background of an individual’s life and living, which has two components: environmental factors and personal factors (World Health Organization, 2001).

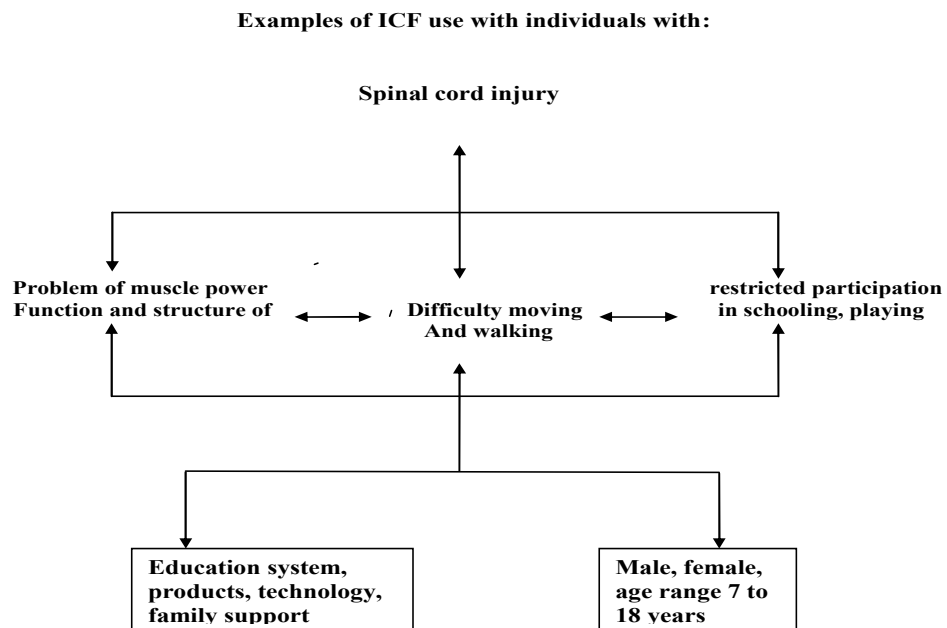


Figure2.2.1 ICF for spinal cord injury patient

2.3 The Impact of spinal cord injury in Participation

There is a negative impact on participation of SCI from the perspective of human functioning, sensory motor and physical limitation and other restrictions (Badia et al., 2015). According to Rosenbaum et al. (2007) SCI is a lifelong injury that has a significant impact on the person’s ability to participate in age appropriate activities in

home, school and community settings. Provability of Participation of SCI at civic life and leisure are reduce due to movement restriction and bowel bladder problem and socialization that influenced by physical limitation (Majnemer et al., 2008). McAleer (2010) also reported that children with disabilities experienced greatest participation restriction for structured events in the community, and social, play or leisure activities with peers either at school or in the community. Engel-Yeger et al. (2009) also reported that SCI children and adolescent have significant lower level participation.

2.4 School:

School is the integral part of the life's of all youth and is critical for psychosocial development and participation of future employment, which is in turn is critical for independent living and life satisfaction as an adult (Anderson 2002). It is imperative that youth with SCI received a well rounded education in the least restrictive environment. In addition primary objective namely academic, youth with SCI mast as fully as possible in extracurricular activities from both Psychological and physical fitness, perspectives youth with SCI should participate in physical education and excess with innovative and accessible program(Chabra 2015). As soon as possible following discharge from the rehabilitation hospitalization the youth with SCI should return to school and ideally the school they attended before. Youth with SCI and their parents are frequently reluctant to resume school for various reason including need for wheel chair, adaptive equipment, need to catheterization and anxieties and about social exclusion. If return to School is delayed it becomes increasingly difficult to for the youth with SCI to return to pre injury life style shortly after discharge from rehabilitation service.

2.5 Barrier for Spinal Cord injury people: Significant improvements in medical management and rehabilitation for individuals with spinal cord injury (SCI) were made in

the past several decades. The emphasis of rehabilitation is shifting from medical management of acute conditions to the challenges that affect quality of life (QOL) and community reintegration, including employment and attaining a higher level of education.(Krause & Birmingham, 2008). The situation for youth and young adults with disabilities, aged 16–26 years, can be particularly disheartening as their vision of themselves as full and active participants in society is typically not fully formed at onset of their disability. (Marcus,et al 2002). Many of the individuals in the targeted age demographic may not have even finished high school or may be in transition between high school and post-secondary education (Birmingham, 2003). A second strong predictor for successful return to or attainment of work is the level of education. For those individuals who have higher levels of education, it is less difficult to return to work after disability (Targett, 2003). Coming to terms with disability, and conceptualizing a ‘different’ future from what may have been previously conceived, are tasks that confront the young adult with SCI. Although systems and services may be in place to assist individuals, it can be very difficult and confusing to navigate the requirements, applications and follow through the procedures needed to successfully access services. However, it is incumbent on each individual to take the initiative to access programs and resources in the community (Targett, 2003).To address this gap in service delivery, ‘Back on Track’ mentoring program was established to improve the community integration of individuals with SCI between the age of 16 and 26. The concepts and practice of mentoring programs in different populations have been studied extensively. Mentoring programs have potential to maximize full integration into society, employment, independent living and economic and social self-sufficiency of individuals with disabilities. With the knowledge of resources within their community, provided by mentors, young adults with SCI can be encouraged to fully participate in social, academic and employment-related activities, improving their QOL. For individuals with SCI, there

have been only few studies that examined ‘supported employment’, and they indicate that supportive employment approach may reduce barriers for return to work. The objective of this mentoring intervention was to improve reintegration of individuals with SCI within an age group that has typically not yet established a solid post-secondary education or employment history. (Targett, 2003)

2.6 Perceived environmental barriers

The inclusion of students with SCI disabilities in elementary and secondary education has not automatically transferred to their inclusion in higher education. Elementary and secondary education and higher education are two quite separate realms in admissions, curriculum, governance, finance, and policy. The top five environmental barriers for SCI patients, natural environment, government policies, transportation, availability of health care services, and attitudes at home. Relatively less problematic were barriers posed by business policies, prejudice, getting help at work/school, and negative attitudes at work/school (Forchheimer et al., 2004, Harrison-Felix, et al

2.7. The factors to improve study participation

1. Scheduling classes and other activities to provide adequate time for a student with mobility problems to get from class to class on time,
2. for a student to get necessary medical or psychological treatment or for a student to adequately rest and recuperate between academic activities,
3. Extending the time for examinations,
4. offering examinations in alternative locations, such a place that is quieter and has fewer distractions than the regular examination location, or providing examinations in alternative formats, such as oral instead of written
5. Priority access to course registration,
6. A special parking space for a persons with SCI for wheel chair, vehicle etc.
7. Wheelchair-accessible desks and tables (Prince George’s Community College, 2003).

2.8 Attitude towards persons with SCI in Bangladesh

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

The World Bank estimates that disabled people make up 15-20% of the poor in developing countries. Poverty has been considered a major factor such as situation. But at the same time the different attitudes and sentiments of the people in families and in communities, also have immense influences in creating such handicapping environments (Islam, 2004). So, most people with SCI suffer from frustration and have an inferiority complex because of their limitation. There is an attitude of neglect regarding their education, job, social activities, food and clothing which may be shared unequally. They are also isolated from participating in recreational and entertainment events (Islam, 2004). So, social change is needed on many levels to create real change. On the other hand, attitudinal changes of the community are one of these changes that will improve the participation SCI people and their access to equal rights in society.

2.9. Importance of rehabilitation in participation:

In a rehabilitation setting, assistive technology and environmental modifications are prescribed to improve a child's functional independence and participation. These accommodations create opportunities but do not ensure a child's effective performance in the school environment. Research on effective uses of assistive technology in school settings is limited, but some concerns are being identified. Paretre and VanBiervliet (1990) suggested that more information about assistive technology need ro be provided to schools and that delivery and use of assistive technology for educational benefits needs

further inquiry. Todis and Walker (1993) explored the daily uses of assistive technology by 13 students with disabilities over a 12-month period. Although student training in use of assistive technology typically occurred at school, preparation of classroom teachers was often lacking. Uses of assistive technology in meeting educational objectives were also seen as inadequate. School staff members sometimes prioritized their own needs for convenience, cost-savings, and keeping on schedule over their student's needs for self-direction, social customs, self-image, and independence. According to Vanderheiden (1987), effective selection and use of assistive technology appear hampered by habits and attitudes rather than by technical limitations. Collaborative efforts between rehabilitation personnel who have access to large numbers of children with SCI and educational personnel who have expertise in classroom and school performance are needed to evaluate such technology and training. Our study sought such collaboration by combining the expertise of occupational therapy, medical rehabilitation, and educational specialists to investigate the experiences of students with SCI. Attention to the effective uses of assistive technology and medical technology systems by students with SCI within school settings has been sparse and review of their educational participation and performance limited. The lack of investigation may be because children under the age of 15 years make up less than 5% of all persons with SCI (Go, DeVivo, & Richards, 1995). Nevertheless, public policy has supported, and now mandates, opportunities for participation of all persons with disabilities. Educational programs and trainings have one of the longest histories of dealing with mandates to provide accessible systems, environments, and assistance to students with disabilities who may have special needs and a reliance on assistive technology. The mandate of accommodation to meet educational participation needs of children and adolescents with SCI dates to 1973 and the passage of Section 504 of the Vocational Rehabilitation Act (Public Law 93-112). Individualization of educational programming to address the needs of children with

disabilities originated in 1975 with the Education for All Handicapped Children Act (Public Law 94-142). In 1990, the spirit of accommodation and individualization were set forth by the Americans with Disabilities Act (Public Law 101-336) and the Individuals with Disabilities Education Act (Public Law 101-476).

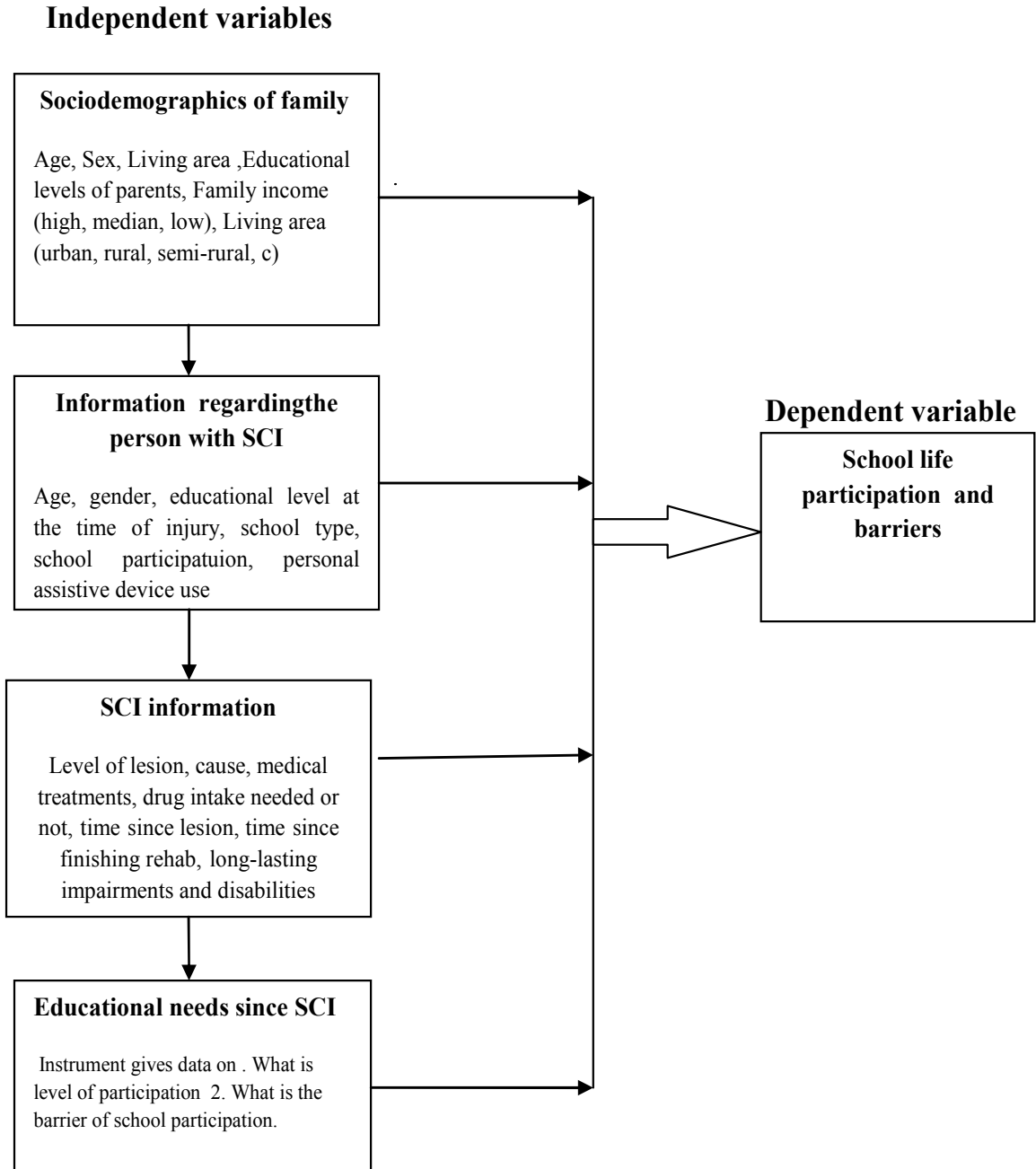
Students with SCI should be accommodated in schools and may qualify for special education and related services when classified under the categories of orthopedic impairment or health impairment. Educators have little information about programming, environmental modification, and use of technology to facilitate school participation and performance of Students with SCI. Educators should have the information about programming, environmental modification, and use of technology to facilitate school participation and performance of Students with SCI.

2.10. Rehabilitation facilities for spinal cord injury in Bangladesh: Though a person with spinal cord injury may face many difficulties in ADLs, many can live long, happy, quality lives. Therefore many young people go on to enjoy near-normal adult's lives if their disabilities are properly managed. The earlier treatment begins the better improvement and development of new skills which is necessary for accomplishing everyday tasks. Traditionally, treatment of SCI has focused on influencing the primary impairments such as spasticity, bowel bladder management, mobility spasticity, or the secondary impairments such as joint contractures. There is limited potential for management of SCI except rehabilitation. Admittedly, their care may involve more visits to health care practitioners, require therapy, medications, and perhaps surgery at some point. Recently, treatment of SCI is increasingly focusing on influencing activities, such as ambulation and self-care. Treatment strategy involves task-oriented intervention and environmental modification for facilitating independence living (Rosenbaum and Paneth, 2006). CRP is a NGO, which has been working for the last 32 years to provide treatment, training,

education, rehabilitation and reintegration for the SCI people in Bangladesh. CRP began as the Rehabilitation Centre for Paralysed Patient (CRP) and was founded on December 11, 1979 by dedicated British woman by the name of Valerie A Taylor (Ahmed, 2006). The vision of CRP is to ensure the inclusion of disabled people into mainstream society and the mission is to promote an environment where all disabled people can have equal access to health, rehabilitation, education, information, and employment. (Ahmed, 2006). The CRP SCI unit provides comprehensive service including Rehabilitation, Reintegration, And community Based rehabilitation through follow up services.

3.1

Conceptual Frame Work



3.2 General Objectives

To explore the School life participation and barriers faced by the student with spinal cord Injury after completion of rehabilitation service from CRP.

3.3 Specific objectives.

- To examine educational participation
- To define the demographic factor and find out if there any association between the demographic factor of school participation and barrier of SCI student
- To identify barriers faced by patients attempting to return to school.

3.4 Study population

The population was spinal cord injured who were student before injury and completed their rehabilitation from CRP Savar, Dhaka and return to their pre morbid occupation as a student.

3.5 Inclusion criteria

- Patients ages 18 years or younger who sustained SCI.
- With resultant paraplegia or tetraplegia.
- Who attended either primary or secondary school.
- Who completed their inpatient rehabilitation from CRP.
- Who were using a wheelchair when discharged from the hospital.

3.6 Exclusion criteria-

- Who have SCI with learning disabilities. Who have problems in a communication, hearing impairment, talking and speech impairments and other problems.
- Student who are studying in CRP inclusive School.
- Spinal cord injury student with head injury.

3.7 Study area

Study was conducted at the community level of the participant Spinal cord injury subject. Most of the participant was from rural area of different division of Bangladesh.

Participant were selected from where CRP community based rehabilitation service patient exist

3.8. Participant selection

After permission of IRB data collection procedure was started. Permission was also taken from the CRP medical unit and CBR unit to search database for sample selection. Data base record was search from the year 2011 to year 2017. Necessary information like name, age, year of injury, telephone number, home district were collected to reach patient through telephone interview. After searching 183 patients were found from records who were student during their discharge. Among them 67 meet the inclusion criteria and 53 interviews were taken because 2 were death 12 was not possible to reach or missing data.

3.9. Study design

This study was prospective quantitative cross sectional research. The researcher used quantitative design for this study. The quantitative study design was selected because quantitative methods help to find out the level of school participation and barrier of participants with statistical values. (Myers, 2009).

3.10 Study period

The study was conducted from December 2017 to May 2018, including data collection, data analysis and write up. Particularly data collection was collected from February, 2017 to April, 2017.

3.11 Sample size

After searching database of CRP 183 patients were found from records who were student during their discharge. Among them 67 meet the inclusion criteria and 53 interviews were taken because 2 were death 12 was not possible to reach or missing data .The researcher took 53 participants who meet the inclusion criteria for the study. In quantitative methodology higher numbers of prospective participants are suitable due to small population and missing data it was not possible to take large number of sample. Since the prevalence of return to study student with SCI in Bangladesh is not available.

3.12 Data collection tools and materials

The semi structured question was used to find out the patients in CRP. Before the start of the research the author conducted a pilot study with five patients to verify whether the questions are easy to understand and the questions are comfortable for the participants. Researcher modified the questions according to pilot study but only with respect to the translation (from English to Bangla).

3.13. Instrument detail

A pre tested semi-structured questionnaire was prepared through literature search and avail best evidence and in a manner that all the variables were measured categorically and the relevant data can be collected. The patients were categorized by age, sex, living area, level of injuries. Information obtaining from the student including school participation domain, barrier domain which include information regarding educational activity participation, social ply, special equipment use, communication with others ,moving around school, and teachers and classmate encouragement activity at school, environmental barrier ,attitudinal barrier. Every single item was categorized into a four point '**Likert scale**'. 4-point scale (4= allays, 3= most of the time, 2= very limited time, 1= never), (Bedell, 2009) (Galvin et al., 2010) (Bedell, 2011). The following criteria are used to rating each item (Bedell, 2009) (Bedell, 2011)

Allays: Participates in the activities the same as or more than other his or her age (with or without assistive devices or equipment).

Most of the time: Participates in the activities somewhat less than other his or her age (may also need occasional supervision or assistance).

Very limited time: Participates in the activities much less than other his or her age (may also need a lot of supervision or assistance).

Never: Participate in the activities, although other his or her age do participate. Finally a list of barrier was given to the participant to indicate least to most barriers at school participation.

3.14. Field test

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

3.15. Data collection procedure

Initially basic demographic information was obtained from medical record. Then subject were contact by phone to complete the questionnaire. For four youngest subject who are in elementary school, assistance in complete the questionnaire was obtained from their mother. All telephone interviews were obtained from one interview to maintain the consistency of the data.

3.16. Data management and analysis

Data were analyzed as per the objectives of the study. Statistical analysis including generation of frequency table, computation of mean, median, standard deviation were done with the help of the computer Statistical Package for Social Science (SPSS). One to four point (1-4) Likert scale was provided for each questions in the questionnaire. Then data were calculated and analyzed by under supervision of an experienced supervisor. During the interview sessions and while analyzing the data, the investigator never tried to influence the process by his own value, perception and biases.

3.17. Quality control and quality assurance

A pre tested semi-structured questionnaire was prepared in such manner that all the variables were measured categorically and the relevant data can be collected .A pre test will be done in small scale after validating the questionnaire. It is important to carry out pre test a before collecting the final data as it helps the researcher to refine the data collection plan.

This will be performed to identify any difficulties that exist in the questionnaires. By finding any difficulties, the investigator will rearrange the questionnaires to make it more understandable, clear and enough for the study.

3.18 Ethical consideration

A research proposal was submitted to the local ethical review committee of Bangladesh health profession institute (BHPI) for being approval. At first we have been applying for official permission for the study from the head of the medical unit of CRP for participant selection. Then the head of the CBR department of CRP had permitted to collect data at community level of different participant. The ethical consideration was making sure by an informed consent of the participants. Consent was obtained by providing each participant a clear description of the study purpose and the procedure in involved in the study. It was also informing the participants that if they wish they can withdraw themselves any time from the study without any consequences for their treatment now and in the future. Participants were explained about their role in the study and it was explained that there is no direct benefit from the study but that in future cases like these may be benefitted from it. Participants are also advised that they are free to decline answering any questions during the interview. The necessary information had been kept on a secure place to also ensure confidentiality. They were also assured that the study could not cause any harm to them. Then if they signed the consent form

After permission of IRB data collection procedure was started. Permission was also taken from the CRP medical unit and CBR unit to search database for sample. Data base record was search from the year 2011 to year 2017. Necessary information like name, age, year of injury, telephone number, home district were collected to reach patient through telephone interview. After searching database of CRP 183 patients were found from records who were student during their discharge. Among them 67 meet the inclusion criteria and 53 interviews were taken because 2 were death 12 was not possible to reach or missing data. Response rate 100%. Subjects are currently studying in 53 different educational institutes, which are mainstream in nature and located in different region of Bangladesh. All subjects were wheel chair user within age range 7 to 18 years.

4.1 Demographics

In terms of the demographic characteristics of children and adolescent with spinal cord injury , out of total respondents there is a predominance of male respondent 50.9% having mean age 15.and standard deviation (SD = 3.03811) and 50.9% have currently studying in secondary educational level and largest age group is 15 to 18 (67.9%) years. Most of them are living in rural and semi rural area respectively (58 % and 28%). Most of the parents of these subjects are illiterate 56.6% with bottom income group 41.5% and middle income group 39.6%. Their incomes mean and standard deviation respectively Mean (SD) 21837.84(15410.158). Business and farming is there primary occupation respectively 28.3% and 24.5% . Table1.1.1 Show the demographic characteristics of the participants.

4.1.1 Demographic information

SCI Participant	n (%)
Age of the respondent	
7 to 10 years	4(7.5)
11 to 14 years	14(32.1)
15 to 18 year	35(67.9)
	*Mean (SD) = 15.5(3.03811)
Gender of the respondent	
Male	27(50.9)
Female	26(49.1)
Living area of the respondent	
Urban	9(17)
Rural	31(58)
Semi rural	13(24)
Current education	
Primary	9(17)
Secondary	27(50.9)
Higher secondary	17(32.1)
Diagnosis	
Tetraplegia	15(28.3)
Paraplegia	38(71.1)
Parents education	
Illiterate	30(56.6)
Educated	23(43.4)
Parents occupation	
Business	15(28.3)
Service	18(34)
Farmer	13(24.5)
Day labor	7(13.2)
Parents income	
Bottom up income	22(41.5)
Middle income	21(39.6)
Top income	10(18.9)
	*Mean (SD) = 21837.84 (15410.158)

(Table 4.1.2) shows the major characteristics, types, severity of the impairments of children and adolescent with SCI and there parents.

4.1.2. Injury Characteristics of SCI subject

	n(%)
Type of impairment	
Paraplegia	38(71.7)
Tetraplegia	15(28.3)
Cause of injury	
Fall from height	24(45.3)
Road traffic accident	19(35.8)
Fall while caring heavy object	2(3.80)
Diving into shallow water	1(1.9)
Neurological level	
C4 to T1	15(28.3)
T2 to T7	7(13.2)
T8 to T12	21(38.6)
Below L1	10(18.9)
ASIA impairment scale	
Complete- A	35(66)
Incomplete-B	18(34)
Incomplete-C	8(15)
Years with injury	
1 to 4 years	42(79.2)
A above 4 years	11(20.8)

Table 4.1.2) shows the major characteristics, types of impairment, Neurological level of injury and level of ASIA impairment scale. This is the table of injury characteristics of child and adolescent with SCI where most of SCI is paraplegia 71.7% having most common 38.6% neurological level between T8 to T12. The most common causes of injury among this population is FFH (45.3%), RTA (35.8). Severity of impairment is categorized by complete and incomplete. Proportionately complete group is predominant 66% where only 15% are the incomplete group. Having this kind of impairment most of them are sustaining with injury within community approximately 1 to 4 year (79.2%).

4.1.3 Distribution of the respondent According to gender and age

	Gender of participant		Total N (%)
	Male N (%)	Female N (%)	
Age of participant			
7 to 10 years	2(3.8)	2(3.8)	4(7.5)
11 to 14 years	8(15.3)	6(11.3)	14(26.4)
15 to 18 years	17(32.1)	18(34)	35(66.1)

4.1.4. This table shows the distribution of respondent according to age range and gender type. In this table most common age range is 15 to 18 and around 66% of the respondent was in this age range among them 32% were male and 34% were female. Most young age group are less dominant respondent in this table only 3.8% male and female are in this group. 15% and 11.3% male and female are the 11 to 14 age range.

4.1.4. School participation of student with SCI

School participation					n (%)
	Allays participate	Most of the time participate	Some times participate	Never	Total reported problem in participation
Participation in educational activity	6(11.3)	25(47.2)	20(37.7)	2(3.8)	74(88.6)
Participation in social play and other recreational activities with others	2(3.8)	7(13.2)	32(60.4)	12(22.6)	51(96.2)
Use educational materials and equipment available at school	4(7.5)	6(11.3)	32(58.5)	12(22.6)	49(92.5)
Communication with peers and others at school	33(62)	16(30.2)	3(5.7)	1(1.9)	20(37.7)
Moving around school and use toilet water fountain, common room	4(7.5)	11(20.8)	22(41.5)	16(30.2)	49(92.5)
Teacher classmate and others encouragement help participation	11(20.8)	14(26.4)	27(50.9)	1(1.9)	42(79.2)

The domains that were designed to examine the school life participation of child and adolocent with SCI or understand the participation level. Most of the participant (88.6%) in terms of participation in educational activitis have some sorts of problem.Using educational material for school activity also reported by big group as a problem (96.2%). Among them majority have(96.2%) problem to participate social play and recreational activities, race, leisure, art, sports with others at school. Where participants were least restricted (37.7%) in communication with their pears, teacher and others at school. Though they less restricted in communication with others but only 7.5% are allays able to move around the school and

access toilet as well as water fountain. Though they have lots of restriction but some them 20.8% get allays encouragement from their teacher and peers for their successful participation in school.

Table 4.1.5 Distribution of participation response level according to gender and injury type

n (%)							
	Allays participate	Most of the time participate	Very rarely participate	Never		Chi value	P value
Participate in educational activity							
Gander	1(1.9)	9(17)	16(30.2)	1(1.9)		.167	.983
Male	1(1.9)	10(18.9)	14(26.4)	1(1.9)			
Female							
Type of paralysis	0(0)	4(7.5)	9(17)	2(3.8)		6.391	0.57
Tetraplegia	2(3.8)	15(28.3)	21(39.6)	0(0)			
Paraplegic							
Participate in play							
Gander	0(0)	22(3.8)	19(35.8)	6(11.3)		.938	.626
Male							
Female	0(0)	3(5.7)	15(28.3)	8(11.3)			
Type of paralysis	0(0)	5(9.4)	26(49.1)	7(13.2)		5.604	.061
Tetraplegia							
Paraplegic	0(0)	5(9.4)	34(64.2)	14(26.4)			
Use of available educational materials							
Gander	1(1.9)	22(3.8)	16(30.2)	7(13.2)		1.376	.711
Male							
Female	1(1.9)	5(9.4)	34(64.2)	13(24.5)			

Type of paralysis	1(1.9)	5(9.4)	23(43.4)	9(17)		2.682	.443
Tetraplegia)				
Paraplegic	1(1.9)	5(9.4)	34(64.2)	13(24.5)			
Communication with peers and others							
Gander	12(22.6)	9(17)	4(7.5)	(3.8)		1.562	.668
Male							
Female	9(17)	9(17)	7(13.2)	1(1.9)			
Type of paralysis	3(5.7)	18(34)	3(5.7)	1(1.9)		4.388	.223
Tetraplegia							
Paraplegic	18(34)	10(18.9)	8(11.3)	2(3.8)			
Moving around school							
Gander	0(0)	5(9.4)	15(28.3)	7(13.2)		2.323	.508
Male							
Female	1(1.9)	6(11.3)	10(18.9)	9(17)			
Type of paralysis	0(0)	3(5.7)	5(9.4)	7(13.2)		3.131	.372
Tetraplegia							
Paraplegic	1(1.9)	8(15.1)	20(37.7)	9(17)			
Teacher and classmates encouragement							
Gander	6(11.3)	6(11.3)	15(28.3)	0(0)		1.692	.639
Male							
Female	5(9.4)	8(15.1)	12(22.6)	1(1.9)			
Types of paralysis	5(9.4)	4(7.5)	6(11.3)	0(0)		2.482	.479
Tetraplegia							
Paraplegia	6(11.3)	10	21(39.6)	1(1.9)			

Table 4.1.7 Distribution of participation response level according to gender and injury type

Table show that the participation according to the gender and type of injury. There is no relationship between gender and type of injury in different level of participation. Where significant p value is <.0005.

4.1.6 Physical change made by the school for participation

Table show that physical change made by the school for their disable student participation is 50.9%. Type of change made by the school is ramp and toilet 37%, class room shift 11.3%.

	Yes n(%)	No n(%)
Physical change made by school for facilitate participation	27(50.9)	26(49.1)
Type of change made by school		
Ramp and toilet	20(37.7)	
Class room shift	6(11.3)	
Furniture rearrange	1(1.9)	

4.2.1

Environmental impact on participation of participant

n (%)					
I					
Response types	Allays problem	Most of the time problem	Very rarely problem	Never	Total reporting problem
Problem regarding availability of transportation	12(26.6)	36(67.9)	5(9.4)	0(0)	53(100)
problem regarding natural environment – temperature, rain terrain,	17(32.1)	12(22.6)	24(45.3)	0(0)	53(100)
Problem regarding design and layout of school buildings	21(39.6)	31(58.5)	1(1.9)	0(0)	53(100)
Problem regarding design and layout of buildings and places in community.	16(30.2)	37(69.8)	0(0)	0(0)	53(100)
Problem regarding availability of personal equipment or special adapted (Examples might include, splint, wheelchairs).	15(28.3)	32(60.4)	5(9.4)	1(1.9)	52(98.1)
Problem regarding classmates and other people's attitudes.	14(26.4)	19(35.8)	20(37.8)	0(0)	53(100)

table define different response rate regarding environmental barrier face by the student for their participation 67%respondent reported availability of transport as barrier while other repotting design of school building as big problem 558.5%. availability of personal equipment big problem for 60% of the respondent while 35.8% and 35% reported most of the time wok as a barer.

4.3. Correlations between Participation with Child and adolescent Environmental Related Problems

Spearman’s rank correlation is used to examine the relationship of school life participation with the environmental barriers. There is a strong moderate inverse relationship between the school life participation and the environmental barrier, $r_s = -0.527$ ($p < 0.001$), that indicate the greater level of participation happened with fewer environment related problem.

4.4. Comparison between Groups in School Participation

A comparison of participation between the group of tetraplegic participant and paraplegic participant indicated a significant difference (Mann-Whitney $U=202$, $P<0.001$). It is indicate that school participation is higher among paraplegic group than the tetraplegic group. Though paraplegic group is higher then tetraplegic groups

Table: 4.4.1

Variables	Group	N	Mean rank	U	Z	P
School participation	Paraplegic	38	32.50	202.5	1.641	.101
	Tetraplegic	15	24.83			

4.4.3 Comparison between groups in each activity of school participation

There is no significant group difference exist between the groups reported in all the activities in the school participation. There is no difference between school participation among male and female (Table 4.7.2). So from the above (Table 4.4.1) and (Table 4.4.2) it is evident that female participant much more effective or fruitful than special education to improve their participation at school. Therefore we may recommend that CP child parents to involve in the inclusive education whenever and wherever it is possible.

4.4.3 Comparison between groups in each activity of school participation

	Activities	Groups	Mean rank	U	Z	P
School participation	Participation in educational activity	Male	27.63	334.	-.344.	.731
		Female	26.35			
	Participation in social play and other recreational activities with others	Male	26.39	334	-.347	.729
		Female	27.63			
	Use educational materials and equipment available at school	Male	26.56	339	-.252	.801
		Female	27.46			
	Communication with peers and others at school	Male	25.57	312.5	-.726	.468
		Female	28.48			
	Moving around school and use toilet water fountain, common room	Male	26.98	350	-.728	.992
		Female	27.02			
	Teacher classmates and others encouragement help participation	Male	27.11	348	-.058	.954
		Female	26.88			

Table 4.2.2. Participants self reported most common to least common barrier

Self reported barrier	Yes n (%)	No n (%)	Total
Health problem	34	19	53(100%)
Lack of transport	47	6	53(100%)
Financial problem	39	14	53(100%)
Lack of accessibility in community	45	8	53(100%)
Lack of family support	30	23	53(100%)
Lack of motivation	30	23	53(100%)

Participants were given a list of factors and asked to indicate how often these factors work as a barrier for school life. The results are presented in table 4.2.2 to simplify the responses. Most of the participant defines lack of transport, lack of accessibility as a major barrier for participation. Lack information resources as one of the important barriers. Approximately 58% of the participant rated lack of research skills as important barrier

Participation in school life is crucial for human being at all ages to health and well-being, skill development and life satisfaction. And it is the ultimate goal for pediatric rehabilitation practitioners. Participation is a new concept in the rehabilitation program and a growing number of tools are used by practitioners and researchers to measure participation and to understand the factors that facilitate or barriers subjects ability to participate with their peers in all aspects of daily life.

5.1. Demographic Information of SCI

Higher prevalence of SCI in our study is lived with their parents who are bottom and middle level income group than the top income group. According to Yeargin-Allsopp et al. (2008) a population-based study in United States shown that the prevalence of SCI was higher among whose families lived in low-and middle-socioeconomic communities (range: 3.9–4.3 cases per 1000) than among those whose families lived in high-income communities (range: 1.8–3.2 cases per 1000) that indicate 70% higher in low- and middle income communities than in high-income communities.

5.2. Characteristics of spinal cord injured population:

Regarding the characteristics of spinal cord injured population we found that there is predominance of male, study had shown that the incidence of SCI in boys (65%) is greater than in girls (35%) (Braccialli et al.,2016). Johnston and Hagberger (2007) also included in their study masculine gender are higher than feminine gender at SCI child. Higher prevalence of SCI boys is consistent with findings of the Yeargin-Allsopp et al. (2008). Manus, Corcoran, and Perry (2008) incorporate information that in their study they found slightly more SCI boys than the girls where 41% of 8-9 years old the highest prevalence. Beside this literature we found that 15-18 years old SCI children in the highest prevalence in our study. Manus et al. (2008) also added information that in their study the highest number of children with SCI

5.3. Correlations between Participation with Child and Environmental Related Problems

Result from our study indicated a positive relationship between environmental restriction and reduced participation of SCI. In our study perspective, moderate inverse correlation between the environmental related problems and the SCI participation where similar result found in case of Australian children that children face negative moderate influence of environmental problems in their home, school and community level participation (Galvin et al., 2010). Galvin et al. (2010) also incorporated another factor (child related) in their study that has also a negative moderate influence on the child's participation in their civic life. But in our study found a moderate inverse correlation between the children related factors and the children participation. According to World Health Organization (2001) participation not only depends on the personal factor, context and environmental factors are essentials for attendance, involvement and participation of children in different life situation. The provision of adequate support of community people, ensuring accessibility in physical structure like building and transportation, disable friendly attitude and provide assistance can facilitate the participation of student with SCI. Opportunity is the key factors for participation that indicate every in all level surrounding should help participate in the civic life activities for well being and improving quality of life (Almqvist & Granlund, 2005).

5.3 Comparison between Groups in School Participation

The study sample was divided into two groups, as follows: male and female In our study the result was indentified significant difference exist in school participation between the male and female group. These results are consistent with previous finding that incorporate evidence on male students group showed significant participation in school function than female student (Schenker et al.,2005).

6.1 Conclusion

This study explored the participation in, school life of children and adolescent with spinal cord injury. The participation and barrier related question has been initially used to measure the participation of spinal cord injury student. Participation is described as different view of the students; students believed that environmental factors contribute this difference. Policy make should focus on this issue. Those findings provided useful information for clinicians to understand the participation that are faced by their client. It is possible to increase awareness of professionals and parents of the barriers and facilitators of participation. That will helpful for therapist to plan, prioritize based on the greatest restriction and implement strategies to enhance participation in the defined time period. Based on the result therapist should involve in environmental modifications and advocacy for change on a community level.

6.2 Limitations of the Study

During the research work it is observed that there has a validation and generalizebility related limitation that are given below as.

- a. Although used the self reported questionnaire was fulfill the purpose of the study but no validation test of scale was done.
- b. The participants was taken from selected area which not generalizable for country perspective.
- c. Evaluate the SCI student school participation based on direct observation that is not representing.
- d. Researcher includes only SCI to measure the participation level that is more representative and comparative if there is include other disabled condition.

6.3 Recommendations

Despite these limitations, this study contributes an understanding of the levels of participation with child and environmental related factors of children living with SCI. Based on the given limitation of the study here focused on the possible recommendation and further studies regarding the participation of SCI children are incorporate below—

- a. There are many factors that may influence the participation of children with SCI; however, this study primarily focused on child and environmental related influential factors. Future studies may be focused on identifying other influential factors with its effect on participation of children with SCI as well as other disabling condition.
- b. Future studies need to investigate difference between the participation and the expectation to identify the overall satisfaction with current level of activity engagement.
- c. Authority and Rehabilitation professional should incorporate the results of the finding and based on this should prepare the intervention plan that provide comprehensive guideline which factors should more prioritize to improve children and adolescent participation at , school and community level that leads further follow up and other hierarchical top level study. e. Carrying out such a study on participation that will represent and possible to generalize at country level. We concluded that greater school participation is depended on the pattern of barrier free environment.

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A.01 (Permission Letter of Institutional Review Board)



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

Ref.

Date: 03/02/18

CRP-BHPI/IRB/02/18/192

To
kameunnaher
Part II, M.Sc. in Rehabilitation Science
Session: 2016-17, Student ID: 181160053
BHPI, CRP, Savar, Dhaka-1343, Bangladesh

Subject: Approval of the thesis proposal “School life participation and barrier of the spinal cord injured students within their community after completion of rehabilitation service from CRP” by ethics committee.

Dear kamrunnaher,
Congratulations.

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

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

Since the study involves answering a questionnaire that take about 20-30 minutes, have no likelihood of any harm to the participants and have possibilities of benefit both for the providers and receivers. The members of the Ethics committee have approved the study to be conducted in the presented form at the meeting held at 9.00 AM on 6th May, 2017 at BHPI.

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

Best regards,

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

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

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

A.02 (Application for Review and Ethical Approval from Supervisor)

Date: 05/03/2018

The Chairman
Institute Review Board (IRB)
Bangladesh Health Professions Institute (BHPI)
CRP, Chapain, Savar, Dhaka-1343, Bangladesh
Subject: Application for review and ethical approval
Dear Sir,

With due respect, I am kamrunnaher, student of part-II M. Sc in Rehabilitation Science at Bangladesh Health Professional Institute (BHPI). As per course curriculum, I need to complete a thesis for completion of my Masters program. Hence, I have to conduct a thesis entitled, **“Perceive barriers of Schooling of the spinal cord injured students within their community after completion of rehabilitation service from CRP”**, under honorable supervisor **Md. Fazlul Karim Patwary**. The purpose of the study is to assess the perceive barriers of schooling of the spinal cord injured students within their community after completion of rehabilitation service from CRP. A self reported Questionnaire will be used by face to face & telephone interview. Related information will be collected from the participants. 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 start data collection. I also assure you that I will maintain all the requirements for study.

Yours sincerely,

-----**Kamrunnaher**
15.04.18

Kamrunnaher
Part-II, M.Sc in Rehabilitation Program
BHPI, CRP, Savar, Dhaka

Recommendation for the thesis supervisor


Md. Fazlul Karim Patwary, 23.4.18

Associate Professor, Institute of IT,
Jahangirnagar University

A.03 (Research Information Sheet-English)

Information Sheet

I am Kamrunnaher, MRS part II student, Department of Rehabilitation science, Bangladesh Health Professions Institute (BHPI), the academic institute of Centre for the Rehabilitation of the Paralyzed (CRP). As a part of my academic issues, I have to conduct a research project in this academic year. So I will like to invite you to participate in my study titled **“School life participation and barriers of the student with spinal cord Injury within their community after completion of rehabilitation service from CRP”**. Your participation in the study is voluntary. You can withdraw your participation in anytime. There is not the facility to get any pay by this participation. The study will never be any harm to you but it will help the service user to know your experience about the discharge process, which is very important for the service provider to plan for their future activities. It will also be helpful for the forthcoming service users. Confidentiality of all records will be highly maintained. The gathered information from you will not be disclosed anywhere except this study and the study will certainly never reveal the name of participants.

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

Kamrunnaher

MRS Part II

Department of Rehabilitation Science

Bangladesh Health Professions Institute (BHPI),

CRP-Chaplain, Savar, Dhaka-1343

A.04 (Research Information Sheet-Bangle)

তথ্যপত্র

আমি কামরুননাহার, বাংলাদেশ হেলথ প্রফেশনস ইনস্টিটিউটের (সি.আর.পিএরশিক্ষাপ্রতিষ্ঠান)এম আর এস পার্ট II রিহ্যাবিলিটেশন সাইন্স বিভাগে অধ্যয়নরত। আমার প্রাতিষ্ঠানিক কার্যের অংশ হিসেবে চলতি শিক্ষাবর্ষে একটি গবেষণা করতে যাচ্ছি। যার শিরোনাম “মেরুদণ্ডে আঘাতপ্রাপ্ত ছাত্রদের সি.আর.পি থেকে পুনর্বাসনের পর কমিউনিটিতে ফিরে স্কুলে অংশগ্রহণে কি কি ধরনের বাধার সম্মুখীন হতে হয়” গবেষণায় আপনার অংশ গ্রহন সম্পূর্ণ সোচ্ছায়। আপনি যে কোন সময় গবেষণায় আপনার অংশ গ্রহন করা থেকে বিরত থাকতে পারবেন। এই গবেষণায় অংশ গ্রহণে গবেষক আপনাকে কোনভাবে আর্থিক সাহায্য প্রদান করবে না। এই গবেষণায় অংশ গ্রহন কখনোই আপনার জন্য ক্ষতির কারণ হবে না, কিন্তু এই গবেষণার মাধ্যমে সেবা প্রদানকারী সদস্যগণ, আপনার অভিজ্ঞতার কথা জানতে পারবেন এবং প্রাপ্ত তথ্য সমূহ সেবার মানোন্নয়নে সাহায্য করবে। যা পরবর্তীতে অন্যান্য মেরুদণ্ডে আঘাতপ্রাপ্ত ব্যক্তিদের ক্ষেত্রে ও সহায়ক হবে। আপনার কাছ থেকে প্রাপ্ত তথ্য সমূহ সর্বোচ্চ গোপনীয়তা রক্ষা করা হবে। অনুসন্ধানকারী এবং অনুসন্ধানকারীর সমন্বয়কারী ব্যতীত এই তথ্য গুলো কোথাও প্রকাশিত কর হবেনা এবং গবেষণার কোথাও অংশ গ্রহনকারীর নাম প্রকাশ করা হবেনা। গবেষণা সম্পর্কিত যে কোন ধরনের প্রশ্নের জন্য নিম্ন লিখিত ব্যক্তির সাথে যোগাযোগ করার জন্য অনুরোধ করা যাচ্ছে।

কামরুননাহার

এমআরএসপার্ট II

রিহ্যাবিলিটেশন সাইন্স বিভাগ

বাংলাদেশ হেলথ প্রফেশনস ইনস্টিটিউট (বি এইচ পিআই)

সিআরপি- চাপাইন, সাভার, ঢাকা-১৩৪৩।

* Translated Copy

A.05 (Consent Form-English)

Consent Form

This research project is part of M. Sc. in Rehabilitation Science course and the name of the investigator is Kamrunnaher. She is a student of Bangladesh Health Professions Institute (BHPI) in B.Sc. in M.Sc. in Rehabilitation Science final year. The study was entitled as **“School life participation and barriers of the student with spinal cord Injury within their community after completion of rehabilitation service from CRP.”**The aim of the study is to find out the School participation and barriers faced by the student with spinal cord Injury within their community after completion of rehabilitation service from CRP.

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

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

I have been informed about the above-mentioned information and I am willing to participate in the study with giving consent.

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

A.06 (Consent Form-Bangla)

সম্মতিপত্র

এই গবেষণাটি এম আর এস পার্ট II, একটি অংশ এবং অনুসন্ধানকারীর নাম কামরুন্নাহার। সে বাংলাদেশ হেলথ প্রফেশন্স ইনস্টিটিউটের (সি.আর.পিএর শিক্ষাপ্রতিষ্ঠান) রিহ্যাবিলিটেশন নসাইন্স বিভাগে অধ্যয়নরত। এই গবেষণার শিরোনাম “ মেরুদণ্ডে আঘাতপ্রাপ্ত ছাত্রদের সি.আর.পি থেকে পূনর্বাসনের পরকমিউনিটিতে ফিরে স্কুলে অংশগ্রহণে কিকি ধরনের বাধার সম্মুখীন হতে হয় ”। এই গবেষণাতে আমি একজন অংশগ্রহণকারী এবং পরিষ্কার ভাবে এই গবেষণার উদ্দেশ্য সম্পর্কে অবগত। আমার যে কোনসময় এই গবেষণা থেকে নিজেকে সরিয়ে আনার অধিকার আছে। এ জন্য আমি প্রশ্নের উত্তর প্রদানের জন্য কারোকাছে দায়বদ্ধ না। এই গবেষণাটির সাথে আমার কোন সম্পৃক্ততা নেই। আমি আরো অবগত আছি যে, এই কথোপকথন থেকে নেওয়া সমস্ত তথ্যাবলী নিরাপদে এবং গোপন রাখা হবে। আমার নাম ও ঠিকানা কোথাও প্রকাশ করা হবে না। শুধুমাত্র অনুসন্ধানকারী এবং অনুসন্ধানকারীর সমন্বয়কারী সাথে এই গবেষণার পদ্ধতি সম্পর্কে অথবা যে কোন প্রশ্নের উত্তর জানার জন্য কথা বলতে পারব।

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

অংশগ্রহণকারীর স্বাক্ষর/টিপসই	তারিখ:
অনুসন্ধানকারীর স্বাক্ষর	তারিখ:
সাক্ষ্য প্রদানকারীর স্বাক্ষর/ টিপসই	তারিখ:

A.06 (Question-English)

Questionnaire

ID No:

Date of interview:

Part–A: Socio-demographic Information of SCI student

S.N	Question	Coding categories	Code No
1	Name: Ageyear	
2	Sex	1. Male 2. Female	
3	Year sustaining with injuryyears	
5	Current education	
	Living area	1.Urban 2.Rural 3.Semiurban	
6	Parents educational status	1. Illiterate 2. Primary 3. Secondary 4.Higher Secondary 5. Graduate	
7	Parent’s occupation?	1. Service 2. Business 3. Farmer 4. Day labor 5. Housewife 6.Unemployd	
8.	Distance of school from house km	
9.	Type of School you are studying?	1. Mainstream 2. Special education 3.Others	
10.	Diagnosis	1. Tetraplegia 2. Paraplegia	
11.	Neurological level	

Section B: School Participation related question

S.N	Question	Coding categories	Code no.
12	How often have you able to participate in educational (academic) activities with others in your classroom at school (reading, writing, homework)?	1. Allays. 2. Some times 3. Very limited 4. Never	
13	How often have you able to participate Social, play and recreational activities with others at school (e.g., “hanging out,” sports, clubs, hobbies, creative arts, lunchtime or recess activities) ?	1. Allays. 2. Some times 3. Very limited 4. Never	
14	How often educational materials and equipment are available for you to use at school?	1. Allays. 2. Some times 3. Very limited 4. Never	
15	How often have you able to communicate (chat and share thing) with other students, teacher and adults at school?	1. Allays. 2. Some times 3. Very limited 4. Never	
16	Have any changes been made to your school setting to help your participation. (e.g., rearranging furniture and materials, adjusting lighting or noise levels, building a ramp or other physical structures)?	1. Yes 2. No If yes what.....	

17	Does any specific staff at school to help you for participating school activities?	Yes No	
18	How often you able to use toilet, water fountain blackboards, and worktables compare to others?	1. Allays. 2. Some times 3. Very limited 4. Never	
19	Does your teacher have positive expectation from you regarding your education?	1. Yes 2. No	
20	How often your teachers encourage you and carefully listen to your views and opinion at class?	1. Allays. 2. Some times 3. Very limited 4. Never	
21	How much emotional support you get from your classmate classmates?	1. Allays. 2. Some times 3. Very limited 4. Never	

Section E: Barrier Related Questions

S.N	Question	Coding categories	Code No.
22	How often has the availability of transportation been a problem for you?	1. Allays. 2. Most of the times 3. Very rarely 4. Never	
23	How often has the natural environment – temperature, terrain, and climate made it difficult to do what you want or need to do?	1. Allays. 2. Most of the times 3. Very rarely 4. Never	
24	How often has the design and layout of buildings and places you use at school made it difficult to do what you want or need to do?	1. Allays. 2. Most of the times 3. Very rarely 4. Never	
25	How often has the design and layout of buildings and places you use in your community made it difficult to do what you want or need to do?	1. Allays. 2. Most of the times 3. Very rarely 4. Never	
26	How often has the design and layout of your home made it difficult to do what you want or need to do?	1. Allays 2. Most of the time	

		3.Very rarely 4.Never	
27	How often has the health problem prevent you to go School?	1. Allays. 2.Most of the times 3.Very rarely 4. Never	
28	How often has the lack of personal equipment or special adapted devices been a problem for you (Examples might include, splint, wheelchairs).	1. Allays. 2.Most of the times 3.Very rarely 4. Never	
29	How often lack of personal assistance at school make a big problem for your school activity participation.	1. Allays. 2.Most of the times 3.Very rarely 4. Never	
30	How often have your classmates and other people's attitudes (ex. bullying, staring) toward you been a problem at school?	1. Allays. 2.Most of the times 3.Very rarely 4. Never	
31	How often did the policies and rules of school make problems for you?	1. Allays. 2.Most of the times 3.Very rarely	

		4. Never	
32	How often did you experience prejudice or discrimination at school or community?	1. Allays. 2. Most of the times 3. Very rarely 4. Never	

33. Participants self reported most common to least common barrier for school participation

- 1. Ill Health.**
- 2. Bowel/bladder problem.**
- 3. Financial problem.**
- 4. Lack of transport**
- 5. Lack of facility in community.**
- 6. Lack of motivation.**
- 7. Lack of support from family.**
- 8. Time constraints.**
- 9. Lack of Safety.**

A.8 (Question-Bangla)

গবেষণার প্রশ্নাবলী		
ক্রমিকনং	প্রশ্ন	ক্যাটাগোরিজ
১	লিংগ	১. ছেলে -২. মেয়ে
২	বর্তমান শিক্ষাগত যোগ্যতা
৩	বসবাসেরস্থান	১. শহর - ২.গ্রাম -৩. মফস্বল
৪	অভিভাবকেরশিক্ষাগত যোগ্যতা	শিক্ষিত - নিরক্ষর
৫	অভিভাবকের পেশা	১..চাকুরি -২ ব্যবসা ৩.কৃষক৪.দিনমজুর ৫. গৃহিনী ৬. বেকার
৬	বাড়ি থেকে স্কুলের দুরত্বকি.মি
৭	স্কুলের ধরন	১.মূলস্লেষ্ঠধারার -২. বিশেষায়িত- ৩. মিশ্র
৮	আঘাতের ধরন	দেঁদ্রাপেলজিয়া - পেরা পেলজিয়া
৯	আঘাতের কারন	১.উচু স্থান থেকে পড়া ২ রোডট্রাফিকএকসিডেন্ট- ৩. অগভির পানিতে ঝাপ দেওয়া ৪.ভারি বোঝাবহনেরসময়পড়েযাওয়া.
১০	কতটা সময় আপনি ক্লাস রুমের পড়াশোনার কাজগুলোতে অংশ গ্রহন করতে পারেন	১.সবসময় ২.বেশিরভাগসময় ৩.খুব কম সময় ৪.কখন ও না
১১	কত সময় আপনি আপনার সহ পাঠীদের সাথে খেলাধুলা,বিনোদন,যোগাযোগ,টিফিন ও সহশিক্ষার অংশ গ্রহনকরতেপারেন	১.সবসময় ২.বেশিরভাগসময় ৩.খুব কম সময় ৪.কখন ও না
১২	কতটা সময় আপনার জন্য প্রয়োজনীয় শিক্ষা উপকরন গুলো সহজ লভ্য	১.সবসময় ২.বেশিরভাগসময় ৩.খুব কম সময় ৪.কখন ও না
১৩	আপনিকতটাসময়আপনারসহপাঠি ও শিক্ষকদের সাথেযোগাযোগকরতেপারেন	১.সবসময় ২.বেশিরভাগসময় ৩.খুব কম সময় ৪.কখন ও না
১৪	আপনারজন্য স্কুলেকি কোনপরিবর্তন আনা হয়েছে যেমন ঢালুপথ আসবাবপত্ত	১.হ্যা ২ না ৩ যদি হয় কি

১৫	স্কুলে নির্দিষ্ট কেউ কি আছে আপনাকে সাহায্য করার জন্য	১.হ্যা ২.না
১৬	স্কুলেরটয়লেট, পানিপানকরারউৎসর্যকবোর্ড আপনারপক্ষেব্যবহারকরাকতটা সম্ভব	১.সবসময় ২.বেশিরভাগ সময় ৩.খুব কম সময় ৪.কখন ও না
১৭	আপনারশিক্ষারব্যাপাওআপনারশিক্ষককতটাইতিবাচক?	১.হ্যা ২.না
১৮	আপনার শিক্ষক আপনাকে উৎসাহ দেয় পড়াশোনার জন্য	১.সবসময় ২.বেশির ভাগ সময় ৩.খুব কম সময় ৪.কখন ও না
১৯	আপনারসহপাঠিদেও কাছ থেকে কতটামানসিকসহযোগীতাপান	১.সবসময় ২.বেশির ভাগ সময় ৩.খুব কম সময় ৪.কখন ও না
২০.	দয়া কও এমন কয়েকটি জিনিসের বর্ণনা দেন যাআপনার স্কুলের কাজে সাহায্য করবে	
২১	আপনার স্কুলে অংশ গ্রহনেরজন্য কোনজিনিস গুলোরব্যাপাওআপনার স্কুল ও কমিউনিটিসাহায্য করতেপারে?	১.সবসময় ২.বেশির ভাগসময় ৩.খুব কম সময় ৪.কখন ও না
২২	কতটা সময় যান বাহনের দূস্থাপ্যতা আপনার জন্য সমস্যা সৃষ্টি করে	১.সবসময় ২.বেশির ভাগ সময় ৩.খুব কম সময় ৪.কখন ও না
২৩	কতটা সময় প্রাকৃতিক দূযোগ রোদে,বাড়, বৃষ্টি আপনার জন্য কতটা সমস্যা সৃষ্টি করে	১.সবসময় ২.বেশির ভাগ সময় ৩.খুব কম সময় ৪.কখন ও না
২৪	কতটা সময় আপনার স্কুলের কাঠামোগত সমস্যার কারণে ,আপনি যাকরতে চানতা পারেন না	১.সবসময় ২.বেশির ভাগ সময় ৩.খুব কম সময় ৪.কখন ও না
২৫	কতটাসময়আপনারএলাকারকাঠামোজনিতকারণে,আপনিযাকরতেচা নতাপারেননা	১.সবসময় ২.বেশির ভাগ সময় ৩.খুব কম সময় ৪.কখন ও না
২৬	কতটা সময় আপনার বাসার কাঠামোজনিত কারণে,আপনি যা করতে চান তা পারেন না	১.সবসময় ২.বেশির ভাগস ময় ৩.খুব কম সময় ৪.কখন ও না
২৭	কতটা সময় শারীরিক সমস্যা আপনাকে স্কুলে যাওয়া থেকে বিরত	১.সবসময়

	রাখে	২.বেশির ভাগসময় ৩.খুব কম সময় ৪.কখন ও না
২৮	কতটা সময় আপনি সহায়ক উপকরণের অভাবে আপনার স্কুলের কাজে অংশগ্রহণ নবাধা গ্রহণ হয়েছে	১.সবসময় ২.বেশিরভাগ সময় ৩.খুব কম সময় ৪.কখন ও না
২৯.	কতটা সময় কাণ্ডে সহযোগীতার অভাবে স্কুলের কাজে অংশগ্রহণ বাধা গ্রহণ হয়েছে.	১.সবসময় ২.বেশিরভাগ সময় ৩.খুব কম সময় ৪.কখন ও না
৩০.	কতটা সময় আপনার সহপাঠি ও অন্যান্যদেও আচরনে বৈষম্যতা স্কুলে অংশগ্রহণে বাধাগ্রহণ করেছে.	১.সবসময় ২.বেশিরভাগ সময় ৩.খুব কম সময় ৪.কখন ও না
৩১.	কতটা স্কুলেরনিয়ম-নীতি আপনার জন্য সমস্যা সৃষ্টিকরেছে.	১.সবসময় ২.বেশিরভাগ সময় ৩.খুব কম সময় ৪.কখন ও না
৩২.	কতটাসময় বৈষম্য মূলক আচরন ও কুসংস্কার আপনার স্কুলে সমস্যা সৃষ্টি করেছে.	১.সবসময় ২.বেশিভাগ সময় ৩.খুব কম সময় ৪.কখন ও না