Health Status and Community Functioning of Adults with Paediatric Onset Spinal Cord Injury Discharged from CRP, Savar

By
Bethi Akther

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This thesis is submitted in total fulfilment of the requirements for the subject RESEARCH 2 & 3 and partial fulfilment of the requirements for the degree of

Bachelor of Science in Occupational Therapy
Bangladesh Health Professions Institute (BHPI)
Faculty of Medicine
University of Dhaka

Thesis completed by:

Bethi Akther
4th year, B.Sc. in Occupational Therapy
Bangladesh Health Professions Institute (BHPI)
Centre for the Rehabilitation of the Paralysed (CRP)
Chapain, Savar, Dhaka: 1343

…….
Signature

Supervisor's name, designation, and signature:

Arifa Jahan Ema
Lecturer
Department of Occupational Therapy
Bangladesh Health Professions Institute (BHPI)
Centre for the Rehabilitation of the Paralysed (CRP)
Chapain, Savar, Dhaka: 1343

…….
Signature

Head of the department's name, designation, and signature:

Sk. Moniruzzaman
Associate Professor & Head
Department of Occupational Therapy
Bangladesh Health Professions Institute (BHPI)
Centre for the Rehabilitation of the Paralysed (CRP)
Chapain, Savar, Dhaka: 1343

…….
Signature

Board of Examiners

Statement of Authorship

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Bethi Akther
4th year, B.Sc. in Occupational Therapy
Bangladesh Health Professions Institute (BHPI)
Centre for the Rehabilitation of the Paralysed (CRP)
Chapain, Savar, Dhaka: 1343

……
Signature

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List of Abbreviations

ADL	Activities of Daily Living
BHPI	Bangladesh Health Professions Institute
CRP	Centre for the Rehabilitation of the paralysed
CBR	Community Based Rehabilitation
CHART	Craig Handicap Assessment & Recording Technique
CI	Confidence Interval
IRB	Institutional Review Board
ICF	International Classification of Functioning, Disability and Health
MCS	Mental Component Score
NGO	Non-Government Organisation
OT	Occupational Therapy
POSCI	Paediatric Onset Spinal Cord Injury
PCS	Physical Component Score
SWL	Satisfaction with Life
SF-V2 Health Survey	Short Form Version 2 Health Survey
SCI	Spinal Cord Injury
SD	Standard Deviation
SPSS	Statistical Package of Social Science
TT	Tetraplegia
TP	Paraplegia
UTI	Urinary Tract Infection

Abstract

Background: Adults with paediatric-onset spinal cord injury is an important issue worldwide. However, it lacks evidence from developing and low-and-middle-income countries.

Aim: the aim of this research was to identify the health status and community functioning of the adults with paediatric-onset spinal cord injury discharged from Centre for the Rehabilitation of the Paralysed (CRP), Savar.

Methods: The study followed a cross sectional quantitative design by conducting telephone survey among 46 participants who received rehabilitation services from the CRP. Standardized questionnaire, SF-12 v-2 health survey to know the health status, Craig Handicap Assessment and Recording Technique (CHART) to know the community functioning of this population were used to collect data. Descriptive analysis was used by SPSS 20 to analyse the data.

Results: 25 male and 11 female with mean current age 25.35, SD (±1.82) responded to the survey. 8.7% responded positive score in the physical health domain and 65.2% scored positive in mental health domain, which means their mental health status was better than physical health status. Among physical independence, cognitive independence, mobility, social reintegration and economic self-sufficiency domains of community functioning, cognitive independence was found as the most prevalent one with 73.9% responding independent in this.

Conclusions: Specialised rehabilitation service for POSCI patients should be introduced by CRP. Barriers of community functioning should be reduced and special consideration should be given to the mobility domain.

Keywords: Health**,** Community, Functioning, Paediatric-Onset, Adult, Spinal Cord Injury

CHAPTER I: Introduction

1.1 Background

People who experience a Spinal Cord Injury (SCI) before the age of 18 years and now are at the age of 19 years or older is known as paediatric-onset SCI (POSCI) adults (Capoor & Stein, 2004; Lee et al., 2009; Osorio et al., 2014). In united states, there is 19.9% children per million people reports POSCI every year (Vitale et al., 2000). Although, there is no prevalence of POSCI globally. Pediatric SCI is less common than adult-onset SCI (Osorio et al., 2014). Those who experience SCI in childhood may have lifelong challenges in health issues such as depression, pain, anxiety, obesity, autonomic dysreflexia and pressure ulcer (January, Kirk, Zebracki, Chlan, & Vogel, 2018; January et al., 2015; Murray et al., 2017; Osorio et al., 2014). They also have challenges in having employment, social support, accessibility, education or having a happy spouse life (Hwang et al., 2014a; Ma et al., 2016; Suttiwong et al., 2015). International Classification of Functioning, Disability and Health (ICF) is a disability and social model proposed by WHO, describes how a health condition such as SCI affects the injured person. They affect the persons health status (anatomical function, physical or psychological health), activities and personal or environmental factors (WHO, 2001).

In terms of health, POSCI adults face mental health and physical health problems (January, Zebracki, Chlan, & Vogel, 2014; January et al., 2015). They face mental health problems due to lack of education, social integration, and unemployment (Caroline et al., 2002; Lawrence et al., 2011; Sylvia et al., 2011). Substance use increased over time among POSCI unemployed adults, mostly they use Marijuana (Hwang et al., 2012). Secondary health complication among POSCI adults also

increases over time (Hwang et al., 2014b; January, Zebracki, Chlan, Lawrence, et al., 2014). These complications reduce their mobility and social participation (Andrade et al., 2019). On the other hand, educated and employed adults have greater mobility than the unemployed POSCI adults. But they face pain in their upper and lower extremity that limits their functional activities of daily living (ADL) (Andrade et al., 2019; Anthony & Winefield, 2002; Hwang et al., 2014a; Hwang et al., 2014b). These are the scenario on USA and Canada. In Bangladesh SCI people faces above mentioned secondary health complications. Pressure ulcer mostly causes death among SCI people in Bangladesh (Hossain et al., 2016; Hossain et al., 2019).

In terms of community functioning, POSCI adults' community functioning significantly dependent on some factors such as education, health outcome, secondary complication, mobility and life satisfaction (Hwang et al., 2014a; Hwang et al., 2014b; Hwang et al., 2015). Some authors found association of community functioning with demographics such as; marriage and area of residence with health and satisfaction with life (Suttwong et al., 2015; Wojtowicz, 2018). There is no association with level of injury or time since injury among adults with POSCI (Suttwong et al., 2015; Wojtowicz, 2018). Educated POSCI adults are employed, and employment integrates them in the society. POSCI adults who are socially integrated is more satisfied with life than unemployed and uneducated ones (Andrade et al., 2019; Bejerholm & Areberg, 2014; Wojtowicz, 2018). In Bangladesh, SCI people has lack of environmental accessibility to be involved in the community (Hossain et al., 2019).

It is documented that, studies regarding POSCI were conducted in the limited geographical area, especially in Canada and Chicago and Philadelphia, United States of America. So, the results cannot be generalized for these population all over the world. In Bangladesh, POSCI adults were not explored at all. It is an important part of

rehabilitation for SCI patients to bring them back to their society and integrate them in the community (Suttwong et al., 2015; Wojtowicz, 2018). The caregiver also has a great concern about their children with SCI and their education, social integration, job and healthy life (House et al., 2009). So, exploring their health status and community functioning after rehabilitation is very important. The SCI evidence in Bangladesh greatly lacks the information about POSCI people. So, a broader perspective needed to develop by exploring the issues among POSCI in Bangladesh. Therefore, this study aimed to identify the health status and community functioning of POSCI adults, discharged from CRP, Savar. This study will create new insight in the field of POSCI in Bangladesh and even in the ASIA region.

1.2 Justification of the Study

To my knowledge, this is the first study to investigate the health status and community functioning of the POSCI in lower and middle economic countries. It is very important to prepare children with or without disabilities for the adulthood as every family has a desire about their child's job and a better adult life (House et al., 2009). However, it is more complicated for children with SCI to be prepared for adulthood in the similar pace of adults without disabilities (Anderson et al., 2006). This research can provide realistic expectations about the patient's rehabilitation outcome in the community to the health care providers or caregivers. Health care professionals will also take necessary measure if there is any alarming status on health of these population. This study will create new insight about the health and occupation status among POSCI in Bangladesh after their transition to adulthood. Patients will also be benefited as the health care providers will know the recent evidence regarding their health and community functioning, so they will be able to plan ahead more precisely with this population during their rehabilitation process. Health care providers especially occupational therapists will be able to use the

evidence in designing community-based rehabilitation (CBR) and vocational training programs more accurately.

1.3 Operational Definition

1.3.1 Health

“Health is state of complete physical mental and social well-being and not merely an absence of disease or infirmity” (WHO, 2015).

1.3.2 Community

When a group of people interact with another is known as a community. This interaction occurs within a geographical bounded territory. They also share same interest and values (Zachary & Neal, 2012)

1.3.3 Functioning

According to ICF, the term functioning refers to “All body functions, activities and participation” (WHO, 2001).

1.3.4 Paediatric-Onset SCI People who had a spinal cord injury before or within 18 years of age and are currently 19 years of age or older are referred to as pediatric-onset injured patients (January, Kirk, Zebracki, Chlan, & Vogel, 2018; January, Zebracki, Chlan, & Vogel, 2014; January et al., 2015, 2017; Kulshrestha et al., 2020; Lawrence et al., 2015; Ma et al., 2016; Vogel et al., 2011)

1.3.5 Spinal Cord Injury

Temporary or permanent damage to the spinal cord that causes changes in its function is known as a Spinal Cord Injury (SCI). The changes cause loss of muscle function, sensation, or function in parts of the body served by the spinal cord below the level of the lesion (Mayoclinic, 2021).

CHAPTER II: Literature Review

This chapter covers the information regarding health status and community functioning of adults with POSCI patients. In terms of health status, this chapter has the information from the existing literatures about the physical and the mental health status. It also includes information's about the community functioning such as, physical independence, cognitive independence, mobility, social integration, occupation and economic self-sufficiency. Paid and non-paid occupations such as adult employment and education, satisfaction with life among POSCI, is also covered in this chapter.

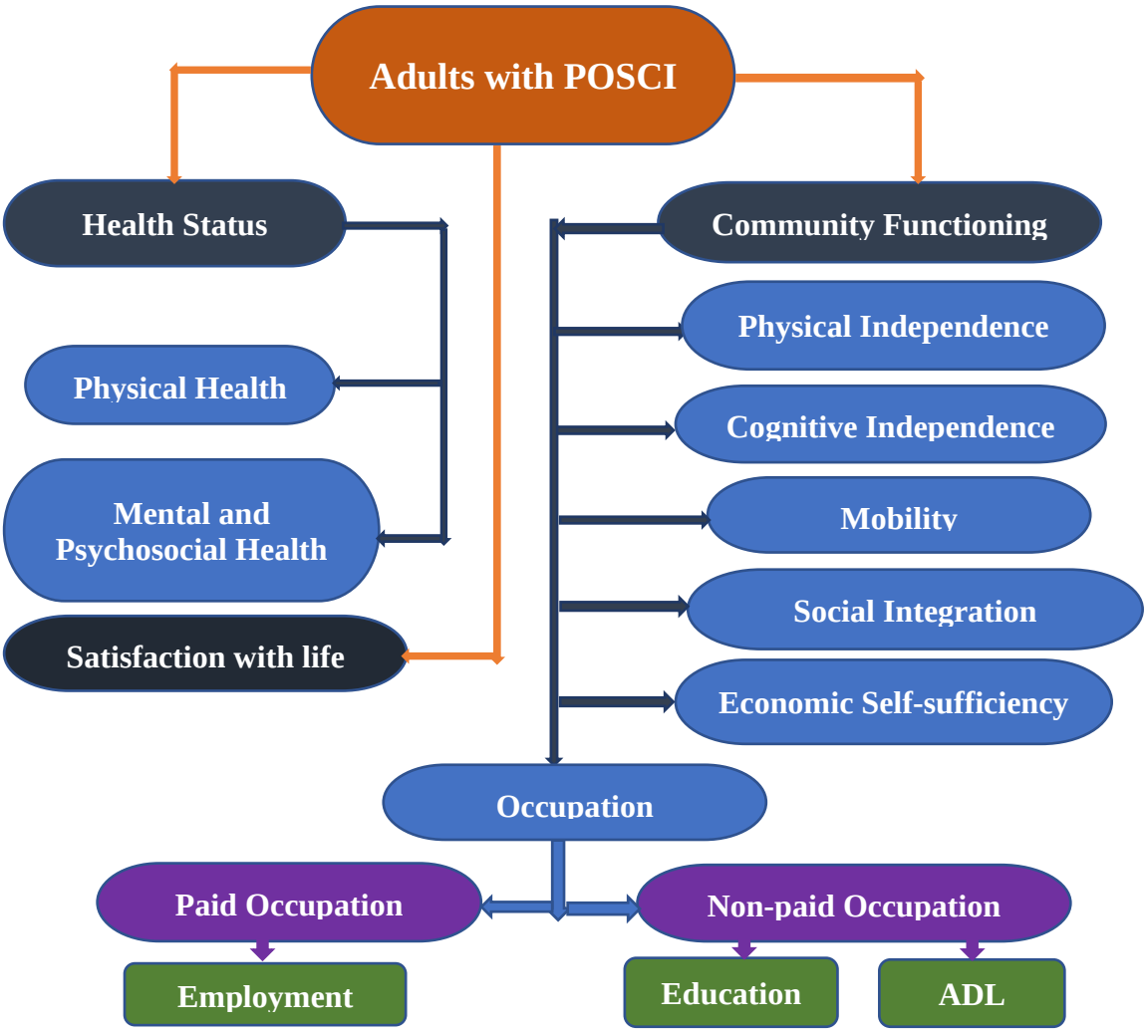

Fig: Overview of literature review findings

2.1 Health Status

This section of the literature review covers the physical, mental, and psychosocial health as well as health related problems of POSCI people.

2.1.1 Physical Health

POSCI people has some physical health problems such as: bodily pain, poor sleep, Urinary Tract Infection (UTI), pressure ulcer, spasticity, spinal deformity, autonomic dysreflexia, hypertension, bowel and bladder management problem and respiratory difficulties (Hwang et al., 2014a; January, Kirk, Zebracki, Chlan, & Vogel, 2018; January et al., 2017; Kulshrestha et al., 2020; Lawrence et al., 2015; Lawrence et al., 2011; Ma et al., 2016; Murray et al., 2017; Osorio et al., 2014; Zebracki et al., 2010). A longitudinal study was conducted with the aim of determining longitudinal employment outcome of adults with POSCI among 283 participants. The study was located on the United States and Canada. Participants were recruited from Shriners hospital for children (Hwang et al., 2014b). They found that, activity time mild to severe neck, shoulder, elbow, and wrist pain limits the performance in daily living activities of POSCI adults. Although it was a longitudinal study, they did not mention the duration of the survey. The same finding was reported by another longitudinal study conducted in the same geographical area among 351 participants. Their aim was to determine longitudinal changes in medical complication among POSCI adults. They took annual interview from 1996 to 2011 and recruited data from the same hospital. However, the participants age during the initial interview was 23 years. So, the adults aged from 19 years to 22 years old were missing from this study (Hwang et al., 2014a). Additionally, a cross-sectional study was conducted in four rehabilitation and research centres in Canada among paediatric versus adults with SCI. They aimed to identify medical complication, function of impairments and life satisfaction among paediatric vs adults-

onset SCI. This study reveals that pain severity is lower to POSCI adults than the adult-onset SCI patients. They added that, upper extremity pain is associated with longer duration of injury (Lawrence et al., 2011). This study participant's age at interview was 24 years. So, again the adults aged 19 years to 23 years were missing in this study. Poor sleep is another significant aspect of physical health problems. Poor sleep, well-being, psychological and medical factors related to pain and activity of POSCI adults were conducted in multiple cross-sectional studies. The study location, setting, age range was same as above mentioned studies (January et al., 2015, 2017; Murray et al., 2017). The prevalence of poor sleep is higher to tetraplegia adults with POSCI than the paraplegia adults with POSCI (Murray et al., 2017). Longer duration of injury among POSCI adults occurs head, neck, hand and wrist pain that interferes their sleep (Murray et al., 2017). On the other hand, lower extremity pain also increases the risk of poor sleep (January et al., 2017). The POSCI adult patients experience secondary complications overtime, such as: hypertension. It increases (4-8%) to the people with POSCI every year (Hwang et al., 2014a). A retrospective longitudinal review was conducted on UK from 1971 to 2013. They aimed to identify the predictors of developing scoliosis among POSCI adults. Data was recruited from the Midland Centre of SCI (MCSCI) among 62 participants only. The study reveals that traumatic injured POSCI adults are less likely to develop scoliosis than the neurological injured POSCI adults (Kulshrestha et al., 2020). The study also suggests that the threshold to develop scoliosis for POSCI patients is 14.6 years post injury (Kulshrestha et al., 2020). Some other secondary physical health complications reported by POSCI adults includes, autonomic dysreflexia, bladder accidents, UTI, respiratory difficulties and pressure injuries (Hwang et al., 2014a). Some authors conducted cross-sectional studies to find out the differences in health outcome and participation among POSCI on Chicago, Canada and

Philadelphia among POSCI adults from the same hospital mentioned above studies. They find that, in comparison of physical health among paediatric-onset vs adult-onset SCI, POSCI adults has better health outcomes, fewer overall visit to physician and less pain comparing to the adult-onset SCI people (January, Kirk, Zebracki, Chlan, Lawrence, et al., 2018; Ma et al., 2016).

2.1.2 Mental and Psychosocial Health

In this section, the principal findings of mental and psychosocial health are depression, Major Depressive Disorder (MDD), anxiety, suicidal thoughts and suicidal ideation (Hwang et al., 2014b; Hwang et al., 2015; January, Kirk, Zebracki, Chlan, & Vogel, 2018; January, Zebracki, Chlan, Lawrence, et al., 2014; January, Zebracki, Chlan, & Vogel, 2014; January et al., 2015; Murray et al., 2017). Several research in the United States of Canada, Chicago and Philadelphia from Shriners hospital for children suggests that adults with POSCI population have prominently depression history (January, Zebracki, Chlan, & Vogel, 2014; January et al., 2015; Zebracki et al., 2010). In case of depression, authors investigated that, violently injured POSCI adults (injury due to accident, trauma, falling, gun shoot etc.) has significantly greater rate of depression than non-violent injured (due to medical condition) (January, Kirk, Zebracki, Chlan, & Vogel, 2018). POSCI people has MDD symptoms, 8% patients had mild to moderate depression which is reported to be increased over time (January, Kirk, Zebracki, Chlan, & Vogel, 2018). However, the incidence of depression is lower to them who are employed and married than the unemployed and unmarried (Hwang et al., 2014a; January, Kirk, Zebracki, Chlan, & Vogel, 2018). The 21% POSCI people reported suicidal thoughts, ideation and severe anxiety (January, Zebracki, Chlan, & Vogel, 2014). Due to suicidal thoughts, some POSCI adults took psychological treatment reported by another study (Murray et al., 2017).

2.2 Community Functioning

This section of literature review covers the information regarding six areas that needed to function or participate in the community found in the existing literatures. The areas of functioning and their effects among POSCI adults is shown as following.

2.2.1 Physical Independence

Physical independence is measured by the number of hours someone needs assistance in a day (Anderson et al., 2016; Caroline et al., 2002; Wojtowicz, 2018) . Several cross-sectional studies were conducted in Chicago and Philadelphia, USA among POSCI adults (Anderson et al., 2016; Caroline et al., 2002; Wojtowicz, 2018). They aimed to identify participation, life satisfaction and changes after transition to adulthood among POSCI adults. The physical independence score among POSCI adults ranges from 79 to 100 where greater score shows better independence (Anderson et al., 2016; Wojtowicz, 2018). Some authors added that, 65% of POSCI adults live independently in USA (Anderson et al., 2016).

2.2.2 Cognitive Independence

Cognitive independence is measured by the judgement, memory and perception of the participants (Anderson et al., 2016; Wojtowicz, 2018). The cognition of POSCI people is higher than other domains of community functioning such as physical independence, mobility, social integration, occupation, economic self-sufficiency (Anderson et al., 2016; Wojtowicz, 2018).

2.2.3 Mobility

The way an individual move around his surroundings is known as the individual's mobility (January, Kirk, Zebracki, Chlan, & Vogel, 2018; January et al., 2017; Lawrence et al., 2015). A longitudinal study was conducted in Chicago, USA aimed to

identify the long-term outcomes of POSCI adults. The authors found that mobility of POSCI adults is higher than adult-onset SCI (Lawrence et al., 2015). They also found that poor mobility affects the general functioning of life (Lawrence et al., 2015). The rate of mobility is associated with secondary health condition (January, Kirk, Zebracki, Chlan, Lawrence, et al., 2018; January et al., 2017). The patients who had pressure ulcers reported less mobility in a study (Hwang et al., 2014a). Some authors conducted cross-sectional study in one of the three branches of Shriners hospital for children. They aimed to identify personal autonomy, life satisfaction and community participation of POSCI adults (Andrade et al., 2019; Kristen et al., 2007; Suttwong et al., 2015; Wojtowicz, 2018). The indoor mobility is reported greater than the outdoor mobility of the POSCI adults that usually limits their recreation and leisure (Andrade et al., 2019; Kristen et al., 2007). Almost 80% of POSCI patients had sufficient indoor autonomy and they faced problematic outdoor autonomy (Andrade et al., 2019). These authors also identified that; transportation is a great barrier for outdoor mobility among POSCI adults.

2.2.4 Social Integration

Social participation depends on the level of injury, independent living, marital status, mobility, education, and employment among POSCI adults (Andrade et al., 2019; Suttwong et al., 2015; Sylvia et al., 2011). Study finds that, educated and employed adults has greater participation in society than the uneducated and unemployed adults with POSCI (Andrade et al., 2019). This study also added that, marriage, family support and independent living with parents improves the social integration.

2.2.5 Economic Self-sufficiency

Economic self-sufficiency is about the earnings of POSCI people and their family (Anderson et al., 2016; Andrade et al., 2019). The median earning of POSCI people is 12000$ per year (Anderson et al., 2016). Studies shows that, employed people lives independently and is economically sufficient (Anderson et al., 2016; Andrade et al., 2019).

2.2.6 Occupation

This section is divided into paid and non-paid occupation where employment information found in paid occupation and non-paid occupation is divided into Education and activities of daily living (ADL).

2.2.6.1 Employment

There are some factors associated with employment, such as, education, mobility, and social integration among POSCI adults (Anderson et al., 2016; Andrade et al., 2019; Hwang et al., 2014b; January, Zebracki, Chlan, & Vogel, 2014). Employment rate among POSCI adult is lower comparing to the adult-onset SCI people (Hwang et al., 2014b). These authors also added that violently injured patients are less likely to be employed than the non-violent injured POSCI patients (Hwang et al., 2014b). Another study suggests that POSCI adults reported employment even without having a college degree or higher education (January, Zebracki, Chlan, & Vogel, 2014). On the other hand, greater level of education shows better employment outcome reported by another study (Anderson et al., 2016).

2.2.6.2 Activities of Daily Living (ADL)

POSCI adults have some difficulty in ADL. One of the reasons behind ADL limitation is pain. Upper extremity joint pain can be mild to severe among POSCI patients, and it limits the activities of daily living that requires hand and upper extremity, as well as lower extremity (Hwang et al., 2014a; January, Kirk, Zebracki, Chlan, & Vogel, 2018). Prolonged use of UL to transfer, wheelchair propel and other mobility is associated with shoulder, elbow and wrist pain that causes activity limitation (Hwang et al., 2014a).

2.2.6.3 Education

Education seems to be a very important part for POSCI people. Education is associated with economic independence, employment, and social integration (Hwang et al., 2014a; January, Kirk, Zebracki, Chlan, & Vogel, 2018; Suttwong et al., 2015; Wojtowicz, 2018). The people who are higher educated has a greater prevalence of being employed than those who are not highly educated. They are also satisfied with life (Hwang et al., 2014b). (Hwang et al., 2012) explored the prevalence of substance use among young adults with POSCI. The study was a cross sectional study located in Chicago, USA. These authors found that POSCI adults who are not having a college degree is using substance and getting depression, such as: Marijuana (Hwang et al., 2012).

2.3 Satisfaction with Life

Life satisfaction of POSCI adults is associated with their education, independent living, family and peer support, marriage, and employment (Hwang et al., 2014a; January, Kirk, Zebracki, Chlan, & Vogel, 2018; Suttwong et al., 2015; Wojtowicz, 2018). Married, educated and employed POSCI adults are satisfied with life (Sylvia et al., 2011). On the other hand, people who had a problematic marriage, unhappy sexual life, and no employment reported lower satisfaction with life (Andrade et al., 2019).

2.4 Key Gaps of the Study

- Majority of the study was conducted in the same hospital that is in Chicago, Philadelphia and Canada and the name of the hospital is Shriners Hospitals for Children. So, the results cannot be generalized all over the world.
- Some studies focused on employment, education and social integration mostly. But other important areas of community functioning such as: physical dependency, cognition and financial dependency was not focused well.
- Education, employment, community functioning issues has not been addressed anywhere other than European countries.
- Even in the United States, the study is limited in a specific hospital.
- In Bangladesh, no study has been conducted regarding POSCI adults.

CHAPTER III: Methodology

3.1 Research Aim, Objectives, and Questions

3.1.1 Research Questions

What are the current health status and community functioning of adults with paediatric-onset spinal cord injury discharged from Savar, CRP?

3.1.2 Aim

To identify the current health status and community functioning of patients with paediatric-onset spinal cord injury after discharged from the Center for the Rehabilitation of the Paralysed (CRP), Savar, Dhaka, Bangladesh.

3.1.3 Objectives

- To identify the health status of POSCI patients after they transitioned to adulthood.
- To identify the community functioning of the POSCI adults in physical independence, cognitive independence, mobility, social integration, occupation, economic-self-sufficiency.

3.2 Research Design

The study followed the cross-sectional study design of quantitative research. The student researcher chose this method because the researcher selected a population from CRP (a specific rehabilitation center) for a specified period (2013 to 2015). Student researcher analysed data over a period of time across a sample population to determine health and community functioning outcomes. This is similar to a snapshot (Setia, 2016). The aim of the study could be achieved with a cross-sectional approach; therefore, the student researcher chose the design of this study.

3.3 Study Period

The study period was between April 2021 to February 2022.

3.4 Study Participants

3.4.1 Study Population

The population of the study is paediatric-onset spinal cord injury people who took rehabilitation service from CRP.

3.4.2 Sampling Techniques

Purposive sampling was used to conduct the study by following the inclusion and exclusion criteria. Purposive sampling is a sampling technique in which the researcher relies on his or her judgment and follows criteria when choosing members of the population to participate in the study (Alchemer, 2021). Therefore, purposive sampling was the best way to select the participants of this study.

3.4.3 Sample Size

$$n = \frac{Z^2 \times pq}{d^2}$$

Here,

n= sample size

z= the standard normal deviate usually set at 1.96

p= 0.5; though the prevalence of SCI is yield, so the quantity of person with SCI is considered as 50% of the total amount of person with a disability (10%) in Bangladesh. q= (1-p) = 0.5; proportion in the target population not having the characteristics. d= 0.5; degree of accuracy required (level of significance/margin of error) According to this equation, the sample should be 80 participants. The student researcher could collect 46 data from the participants of this study.

3.4.4 Inclusion Criteria

- Participants who sustained an SCI at age 18 years or younger.
- Participant aged between 19 years to 35 years at the time of interview.
- Participants who took rehabilitation service from CRP between 2013 – 2015 and returned to their community.

3.4.5 Exclusion Criteria

- Participants who had a significant brain injury
- Participants who received rehabilitation service from the out-patient of CRP
- Participants who do not have a valid phone number in the CBR department

3.4.6 Participant Recruitment Process

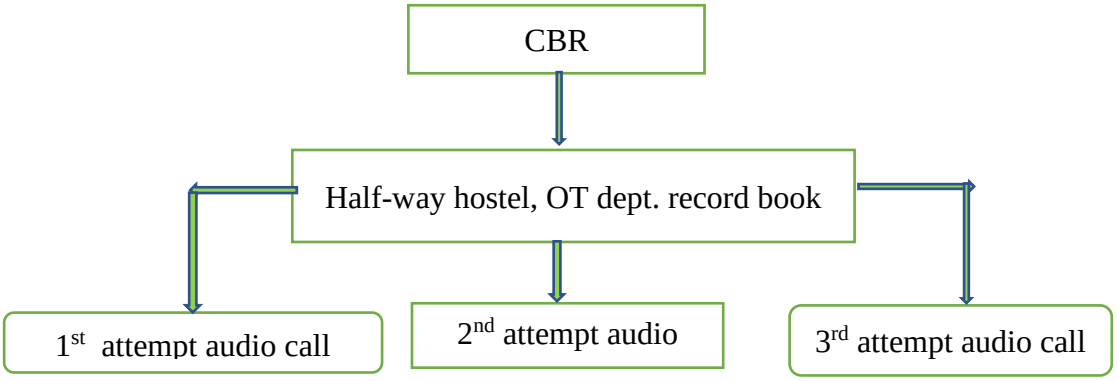

Fig: Overview of participant recruitment process

The student researcher contacted the record book of the CBR department, CRP and halfway hostel OT Department, CRP to collect information of the participants. Student researcher collected the name, type of injury, age of injury, year of leave, date of injury and contact numbers of the participants. Following the inclusion and exclusion criteria, potential participants were listed to collect data

3.5 Ethical Considerations

3.5.1 Consent from IRB

The ethical clearance has been sought from the Institutional Review Board (IRB) explaining the purpose of the research, through the Department of Occupational Therapy, Bangladesh Health Professions Institute (BHPI). IRB form number: CRP/BHPI/IRB/523. Permission from the CBR department and OT SCI dept. also taken before taking participants information.

3.5.2 Informed Consent

The student researcher explained the purpose of the research to the participant, those who felt willing to participate, their data was collected. Verbal consent was taken from the participants as they have been interviewed over the phone.

3.5.3 Right of Refusal to Participate or withdraw

In this study, participants were free to choose, whether to participate or not. They were also free to withdraw participation from the study within 2 weeks from the time of interview.

3.5.4 Confidentiality

The information provided by the participants was confidential. Their name and identity were not disclosed to anyone except for the supervisor and it was stated on the information sheet. The participants were informed that their identity will remain confidential for future uses, such as report writing, publication, conference or any other written materials and verbal discussion.

3.5.5 Unequal Relationship

The student researcher did not have any unequal or power relationship with the participants.

3.5.6 Risk and Beneficence

The participants did not have any risk and they did not get any beneficence from this research.

3.6 Data Collection

3.6.1 Data Collection Method

The data were collected by the telephone survey. Participants were communicated over phone because face to face interview was not possible for the student researcher as the participants were from different districts of Bangladesh. So, telephone survey helped to collect data within short time from different districts (Toole et al., 2008). Not only that, during this ongoing pandemic of Covid-19, it was not possible for the student researcher to travel in the community. It was equally risky for the patients as well as for the researcher. So, data has been taken over the phone.

3.6.2 Interview Guide/ Survey Tool

SF-12 V-2 Health Survey

short form of health survey version 2 contains two domain that is physical component score (PCS) and mental component score (MCS). The scale is a 12-question health survey where average physical component score is 50 and average mental component score is 42. Greater score indicates better health (ware et al., 1998). In this study the SF-12 V-2 health survey was used to find out the health status of POSCI population.

Free online SF-12 Orthotoolkit was used to calculate the average PCS and MCS score of the participants (Orthotoolkit, 2022).

Craig Handicap Assessment and Recording Technique (CHART) short form

CHART is a standardised questionnaire that is consist of six domains and the domains are physical independence (number of hours needs to take assistance), cognitive independence (ability to supervise, memorise and judgement), mobility (ability to move around, hours and days out of bed, house or spend any nights out of house other than hospitalization), social integration (how many people lives with, marital status, visits to relatives, communicating friends and strangers), occupation (hours per working in a job, hours spend in education, involvement with any organization, doing home management and leisure activities) and economic self-sufficiency (personal or family income including disability alliance per year considering health expenses). Each of the domains have 100 scores where 100 score indicates independent on the respective domain and less than 100 score indicates dependency on the respective domain (Whiteneck et al., 1998). This tool was used in this study to find out the community functioning of POSCI adult population (See appendix C for the full questionnaire).

3.7 Data Management and Analysis

The document was presented in the Microsoft office word and the Microsoft office excel were used to make bar chart and tables. The data collected from the participants were initially stored in a excel database to be sure the date and time of the data collection and to record the number of attempts to call. After that the researcher input data in the SPSS. Descriptive statistics was used to analyse the data by using the Statistical Package for Social Science (SPSS) v20.

3.8 Quality Control and Quality Assurance

The proper quality of data was assured and managed by the student researcher. Firstly, Data was recorded in a excel spreadsheet to keep the track of number of calls. The excel spreadsheet also helped to give proper information about how many participants did not receive the call. Then, the data were input in the SPSS. Missing data was checked properly. All the data were input properly and assured by the student researcher. The student researcher also checked the data with her responsible supervisor.

CHAPTER IV: Results

This chapter represents the findings of the study. The chapter contains the study findings in tables and figures focusing the socio-demographic information, community functioning status and health status of the adults with POSCI patients.

4.1 Socio-Demographic Characteristics

Table 1 Socio-demographic characteristics

Variable	Category	N=46	Percent (%)
Sex	Male	35	76.1%
	Female	11	23.9%
Age at Injury	Age in Years	Mean age at injury 16.20, SD (±1.6)	
	Maximum age at injury	18	
	Minimum age at injury	13	
Current age	Age in years	Mean age 25.35 years, SD (±1.82)	
	Minimum Age	21	
	Maximum age	28	
Type of paralysis	TP	35	76.1%
	TT	11	23.9%
Injury Duration	Duration in years	Mean Injury duration 7.87 years, SD (.778)	
Previous work	Student	46	100%
	Others	0	0%
Current work	Unemployed	13	28.3%
	Student	17	37%
	Paid job	3	6.5%
	Business	10	21.7%
	Others	3	6.5%

The table 1 shows an overview of socio-demographic information of POSCI people including the participants' sex, age at injury, current age, injury type, injury duration, their previous work, and current work status. Male were more than (76.1%) female (23.9%) in this study. The group of participants of the study had their injury during paediatric period and they were adult during data collection. Their mean age at injury was 16.20 years, SD (±1.6) and the age at injury of this population lied between 13

years to 18 years. In the adulthood, the current mean age was 25.35 years and their age ranged from 21 years to 28 years, (SD ± 1.82). Participants mean injury duration or time since injury was found 8 years, (SD ± 0.778) which means the participants were living with SCI for about 8 years. Paraplegic participants (76.1%) were more than the tetraplegics (23.9%). Moving on now to consider their previous and current work status, table 1 showed that the previous work status of this population of the adults with POSCI people was student (100%, n=46) and currently after their rehabilitation, only 37% (n=17) participants reported as student. There is a variation in post rehabilitation work status. It showed that 21.7% (n=10) participants were running business, 6.5% (n=3) were employed in different organisation and 6.5% doing other paid works such as freelancing. Additionally, 28.3% (n=13) of the participants' have reported that they have no current work status which is a negative finding and indicates that they have dropped out of education and other productive works as well.

4.2 Health Status of the Participants

Table 2 PCS and MCS health status

Variable	Category	Frequency (n=46)	Percent (%)
PCS Score	Negative	42	91.3%
	Positive	4	8.7%
	Mean PCS (95% CI)	40.36	
	Upper Bound	42.83	
	Lower Bound	37.89	
	Minimum	20	
	Maximum	54	
	Std. Deviation	8.323	
MCS Score	Positive	30	65.2%
	Negative	16	34.8%
	Mean (95% CI)	47.09	
	Lower Bound (95% CI)	43.85	
	Upper Bound (95% CI)	50.33	
	Minimum (95% CI)	25	
	Maximum (95% CI)	62	
	Std. Deviation	10.906	

The table 2 presents the findings of health status among adults with POSCI people of this study. SF-12 V2 health survey questionnaire was used to assess the health status of this population. The table 2 shows the health status in two domains: Physical Component Score (PCS) score and Mental Component Score (MCS). As shown in the

table 2 the physical component mean score was 40.36 and this score lies between 37.39 to 42.83 with 95% Confidence Interval (CI), SD ±8.323. According to the instruction of the SF-12 scale, the average score for the PCS domain is 50. Only 8.7% people reported the score above 50 and majority (91.3%) of the population scored below 50. So, the findings of PCS score indicates that the physical health status of this population was poor. The table 2 also shows the findings on the mental health status of this population in the study. In the bottom of the table, the MCS health status findings shows that 65.2% people of the study reported score above the average mental health threshold score that is 42 according to the SF-12 scale instruction and 34.80% participants reported score lower than 42. The mean MCS score is 47.09 with 95% confidence interval which lies between 43.85 to 50.33 with 95% CI, SD± 10.906. The minimum mental component score is 25 and the maximum mental component score is 62. So, the finding suggest that the mental health status is good comparing to physical health among POSCI adults.

4.3 Community Functioning

In community functioning, there are six domains, such as physical independence, cognitive independence, mobility, occupation, social integration, and economic self-sufficiency. The findings indicate that that the lowest independent area of this population is mobility area, and the highest independent area of this population were cognitive independence.

Table 3 characteristics of community functioning

Domain	Category	Frequency (n=46)	Percent (%)
Physical Independence	Yes	18	31.1%
	No	28	60.9%
Cognitive Independence	Yes	34	73.9%
	No	12	26.1%
Mobility	Yes	6	13%
	No	40	87%
Occupation	Yes	11	23.9%
	No	35	76.1%
Social Integration	Yes	12	26.1%
	No	34	73.9%
Economic self sufficiency	Yes	7	15.2%
	No	39	84.8%

Yes = Yes indicates the participants score is >100 and independent on that domain

No = No indicates the participants score is <100 and dependent on that domain

4.3.1 Physical Independence

In this domain, the term "physical independence" generally means need for assistance in the activities of daily living such as eating, bathing, dressing, toileting, and mobility. When someone scores 100 and above, it is considered 100 and independent in this domain. 31.1% people (n=18) were independent in their daily activities such as eating, bathing, dressing, toileting, mobility and did not need assistance doing these activities on the other hand more than a half of the population (n=28) scored lower than 100 (60.9%) that means these population needed assistance in their daily activities that is mentioned above.

4.3.2 Cognitive Independence

Cognitive independence was measured based on remembering, decision making and judgement. In this domain the population of this study has a greater score of independence among all the domains of community participation measured by CHART.

Table 3 showed that 73.9% (n= 34) was independent in cognition. On the other hand, 26.1%(n=12) population had dependency in cognitive domain.

4.3.3 Mobility

The term “mobility” is referred to the individuals moving out of bed in a day, out of house in a weak and spending nights out of house in a year without hospitalization.

Table 3 showed the highest dependency on mobility among all other domains of CHART. Only 13% (n=6) people were mobile in this domain and the rest (87% (n=40) were dependent in mobility.

4.3.4 Occupation

The term “occupation” refers to work, education, home making, parenting, and leisure activities. Only 23.9% people scored 100 and the rest of the 76.1% people scored below 100 which means the majority of the population is dependent on the above-mentioned areas of occupation and a very minimal number of people (n=35) were independent.

4.4.5 Social Integration

“Social Integration” term measures with how many people the individual with POSCI lived with. Whether they lived with their spouse or relatives, whether they were engaged in business organizations or not. They have friends or not and also, they take an initiative to communicate with strangers or not. Table 3 community participation of the adults with POSCI showed that 26.1% people were socially integrated as they scored 100 and 73.9% people were socially not integrated as they scored below 100.

4.3.6 Economic Self-Sufficiency

The term “economic self-sufficiency” measured the annual earning of the individual that includes his family incomes and disability allowance. Subtract the yearly expenses on health maintenance of the individual from the annual earning and measured it according to the level of poverty. In this study these annual earnings were taken in Bangladeshi currency (taka) and then it was converted in dollar on 20th December where dollar rate was 1$= 80 taka (Exchange Rates, 2021). After that poverty level were estimated according to world bank poverty level of Bangladesh. In the bottom of the table 3, the economic self-sufficiency is showed where only 15.2% people scored 100 and rest of the 84.8% people scored below 100 which means that most of the population were dependent on the area of economic self-sufficiency. All the domains of community functioning of the adults with paediatric-onset spinal cord injury and their score shows that without the cognitive domain, the majority of the respondents scored negative in all the other domains. This result clearly indicates that the community functioning of the population of this study was poor.

CHAPTER V: Discussion

This study aimed to identify the the current health status and community functioning of patients with paediatric-onset spinal cord injury after receiving rehabilitation services from. It was a telephone survey with the response rate 60.2%.

In this study, the mean age at injury of the pediatric-onset SCI people were 16.20y, which was not exactly matched with previous studies, but the close was found as 15 years (Lee et al., 2009). The mean age at interview in this study was 25.35 years when other authors found as 25 years (Ma et al., 2016), and 27.3 years (Caroline et al., 2002). (Lawrence et al., 2015). One interesting finding in the socio-demographic characteristics shows that the type of injury or the level of injury is 76.1% paraplegia and 23.9% tetraplegia in this study which has variation with other studies. Other studies shows that tetraplegic group of people is larger than the paraplegic group of people, such as 56.1% tetraplegic (TT) and 43.9% paraplegic (TP) (Murray et al., 2017), tetraplegia 57.9% and paraplegia 42.1% (January, Zebracki, Chlan, & Vogel, 2014), 61.5% TT & 38.5% TP (Hwang et al., 2014b). It is difficult to explain the reason behind this inconsistency, however it can be the result of variation in histories of accidents in different geographical locations of the world.

Another important socio-demographic characteristic was that the previous working status of the population in this study was 100% students and the job status after injury shows that only 37% of the population are students, 28% have no current job, 21% are doing business, 6.5% are jobs and 6.5% of people are doing other things like: Freelancing. As noted in the literature review, several studies have found that the unemployment rate is higher than the employment rate (Caroline et al., 2002; Hwang et al., 2014b; Hwang et al., 2015) which was consistent with this study findings. A

possible explanation for this could be the level of injury and education because previous literature shows that higher level of education is associated with employment (Caroline et al., 2002; Hwang et al., 2014b) and this study shows a good number of participants' current occupation is "student". As people who have better education are more involved with employment (Caroline et al., 2002; Hwang et al., 2014b; Hwang et al., 2015) it could be further research on employment rates, education and their association in Bangladesh.

The first objective of this study was to determine the health status, both physical and mental health of the pediatric onset SCI people. It was an interesting finding that, the mental health component score is good in this population than the physical health. Evidence also suggests that the level of depression, life satisfaction, rate of substance use, poor sleep and pain is associated with education and employment (January, Kirk, Zebracki, Chlan, & Vogel, 2018; January, Zebracki, Chlan, & Vogel, 2014; January et al., 2015, 2017; Ma et al., 2016; Vogel et al., 2011; Zebracki et al., 2010). However, this study could not find out the association of physical or mental health with level of injury or other factors so this could be an important issue for further research.

The second objective of this study was to identify the community functioning of pediatric-onset SCI people. It found only 31.10% adults with POSCI were physically independent which was not constant with previous literature (Anderson & Vogel, 2003; Caroline et al., 2002; Lawrence et al., 2011). the possible reason maybe the because of the western people have more facilities technologically then the lower or middle economic countries. In this study, the cognitive independence was found as the highest level of independent (73.90%) area. Previous studies also reported greater cognition among POSCI but they did not mention the percentage (Anderson & Vogel, 2003; Caroline et al., 2002; Lawrence et al., 2011). The investigator observed that the patients

who were bed ridden or had lower amount of mobility scored lower level of cognition. It is a hypothesis and can be a matter of further research to know the association between mobility and cognition among POSCI patients. Only 13% population were independent in mobility in this study which is lowest among all the domains of community functioning. Previous studies mentioned the association between mobility and employment or life satisfaction but did not investigate the prevalence of mobility among POSCI adults (Anderson & Vogel, 2003; Anderson et al., 2016; Anderson et al., 2006; Andrade et al., 2019; Lawrence et al., 2011). Only 26% POSCI adults were socially integrated as previous studies agreed that there is a relation between mobility, social participation, and employment. So, low level of mobility may affect all other domains of community functioning which is also a hypothesis as this study did not investigate any correlation. Further work could be done to investigate this associations. This study also found that only 15% POSCI people were economically sufficient. Existing literature suggests that people who are economically independent were satisfied with life and also lives independently, so the adults of this study is satisfied with life or not should be investigated. In the occupation status only 23.90% people were independent. The POSCI adults from United States showed that 58% were employed where in this study it is very low. The possible reason could be the change in geography and also the poor education status of the population in this study. The low level of mobility and physical dependency can be another cause of scoring low in the occupation domain. So, this study is indicating that the occupation status that includes both paid and non-paid occupation is very poor among this population group. Prior studies did not note the occupational status of the POSCI people, however they studied for employment and occupational characteristics which is indicated toward the paid occupation only (Capoor & Stein, 2004; Caroline et al., 2002; Hwang et al., 2015). The

researcher found that, there was a majority of people who scored near to 100, so 76.1% people who scored lower than hundred has a variety of status for occupational and other domains of dependency. So, if these population could be addressable, the result would be clearer and more effective.

CHAPTER VI: Conclusion

6.1 Strengths and limitations

6.1.1 Strengths

- This was the first study among adults with paediatric-onset SCI in Bangladesh
- SF12v2 Bangla questionnaire was culturally validated, author permitted to use the tool.
- The study was time effective
- The researcher could have wide geographical variation of participants, as it was a telephone survey
- Study response rate was 60.2%. As telephone response is low, previously discussed in literatures, (Toole et al., 2008) it was a great strength of this study.

6.1.2 Limitations

There are some limitations of the study. They are,

- The participants were based on a specific rehabilitation centre, which made the population of the study a small group of people. Hence there was a small number of participants (n=46).
- There were multiple invalid phone number the database which restricted to reach the overall population (n=23).

The study is a telephone survey which have some limitations such as

- lack of visual materials that made difficult to build up rapport with the respondent
- inability to access telephone numbers which were invalid
- some participants did not pick up the calls despite three attempts made

6.2 Practice Implication

6.2.1 Institution based practice implication

The current rehabilitation practice and return to work project in CRP is based on adults with Spinal SCI. So, early rehabilitation and return to work strategies should develop for POSCI patients. So that they can be prepared for their adulthood from the very early stage of rehabilitation. CRP should introduce a specialised rehabilitation centre for POSCI patients.

6.2.2 Community based practice implication

The Occupational Therapists should be the advocate of their patient in the community. They should aware the family as well as the living community of the POSCI patient. Should aware the community about needs, challenges and rights of POSCI adults.

6.2.3 Recommendation for further research

Some research recommendations are as follows:

- Identify the association between sociodemographic characteristics and community functioning
- Identify the association or inter-relation among the areas of community functioning
- Explore the life satisfaction of POSCI adults
- Explore the quality of life and association of socio-demographics with quality of life
- Identify the caregivers' satisfaction with the rehabilitation of POSCI adults

6.3 Conclusion

The purpose of this study was to determine the current health status and community functioning of adults with paediatric-onset SCI. This is the first report on health status among this population group in Bangladesh. The study contributes to our understanding of the socio-demographic characteristics and current status of this population. The study has found that the physical health status among this population is poor, but the mental health status is good. The research has also found that the post rehabilitation community functioning among POSCI adult is very poor. So, the rehabilitation should focus more on community-based rehabilitation to enhance their life satisfaction, reduction of physical dependency and increase mobility as well as occupation. The current data highlights that this adult has a well mental health status so they can be more productive in their occupational engagement if they can overcome the physical health problems. Although this study focuses on the general physical health and mental health status, but the specific health issues and secondary health conditions should also be considered among this population.

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APPENDICES

Appendix A: Ethical Approval Form

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

Ref: CRP/BHPI/IRB/11/2021/519 Date: 14/11/2021

Bethi Akther
4th Year B.Sc. in Occupational Therapy
Session: 2016-17
BHPI, CRP, Savar, Dhaka- 1343, Bangladesh

Subject: Approval of the research project proposal**"Health Status and Community Functioning of Adults with Paediatric Onset Spinal Cord Injury Discharged from the CRP, Savar"** by ethics committee.

Dear Bethi Akther,
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 and Arifa Jahan Ema, Lecturer, Department of Occupational Therapy, Bangladesh Health Professions Institute (BHPI), CRP as thesis supervisor. The Following documents have been reviewed and approved:

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

The purpose of the study is to determine the current health status and community functioning of adults with paediatric onset spinal cord injury discharged from CRP, Savar. The study involves use of tools SF12V2 and CHART short form to identify health and community functioning. There is no likelihood of any harm to the participants and or participation. There is no benefit to the participants.Should there any interpretation, type, spelling and grammatical mistakes in the title, it is the responsibilities of the investigator. Since the study involves questionnaire that takes maximum 20 minutes and have no likelihood of any harm to the participants, the members of the Ethics Committee approved the study to be conducted in the presented form at the meeting held at 9.15 AM on the 15th September, at BHPI (29thMeeting).

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

CRP-Chapain, Savar, Dhaka-1343, Tel : 7745464-5, 7741404
E-mail : principal-bhpi@crp-bangladesh.org, Web: bhpi.edu.bd, www.crp-bangladesh.org

Appendix B: Information sheet and consent form [English Version]

Participants Information and Consent sheet

Research topic: Health status and community functioning of adults with pediatric-onset Spinal Cord Injury discharged from CRP, Savar

Researcher: Bethi Akther, B.Sc. in Occupational Therapy (4th year), Session: 2016-2017, Bangladesh Health Professions Institute.

Supervisor: Arifa Jahan Ema, Lecturer in Occupational Therapy, Department of Occupational Therapy, Bangladesh Health Professions Institute.

Place of Research: The study will be conducted in the community over mobile phone

Part-1 Information sheet:

Introduction

I am Bethi Akther, student of 4th year B.Sc. in Occupational Therapy session (2016-2017) studying under the Medicine Faculty of Dhaka University in Bangladesh Health Professions Institute. To complete B.Sc. in Occupational Therapy from BHPI conduct a research project is mandatory. This research project will be done under the supervision of Kaniz Fatema, Lecturer in Occupational Therapy. The purpose of the research project is the collection of data and how it will be related to the research and this will be presented to you in detail through this participant paper. If you are willing to participate in this research, in that case the clear idea about the research topic will be easier for decision making. Of course, you do not have to make sure you participate now. Before taking any decision, you can discuss with your relatives, or guardian about this. On the other hand, after reading the information sheet if the participant's problem to understand the content or if you need to know more about something, you can ask.

Research Background and Objectives

You are being invited to be a part of this research because in Bangladesh, there is no research on paediatric-onset adults with spinal cord injury. It will investigate their health and occupation status. Your information will be helpful to reveal the health and occupation status of this population through your voluntary participation in this study.

Let's know about the topic related to participation in this research work

Before singing the consent form from you, the details of managing the research project will be presented to you in detail through this participation note. If you want to participate in this study, you will have to be agree to participate in the study. If you ensure the participation, a copy of your consent will be given. After a representative of collection data till by the researcher will call you. At any given time taken from you by a question paper information will be collected. Your participation in this research project is optional. If you do not agree then you do not have to participate. Despite your consent, you can withdraw your participation at any time without giving any explanation to the researcher.

The benefits and risks of participation

You will not get any benefit directly to participate in this research project. Participation in this study can lead to many difficulties in your daily work. However, we are hopeful that the benefits direct from the results of this research will remove the disadvantages. Don't worry about the questions that may know about your identity, it's a request. Patient's name, address will not be included in the data analysis software to reduce the risk of uncover identity.

Confidentialities of information

By signing this agreement, you are allowing the research staff to study this research project to collect and use your personal resources. Any information gathered for this

research project, which can identify you, will be confidential. The information collected about you will be mentioned in a symbolic way. Only the concerned researcher and supervisor will be able to access this information directly. Symbolic ways identified data will be used for the next data analysis. Information sheets will be kept into a locked drawer. Electronics version of data will be collected in BHPI's Occupational Therapy department and researcher's personal laptop. It is expected that the results of this research project will be published and presented in different forums. In any publication and presentation, the information will be provided in such a way that you cannot be identified in any way without your consent. Data will be initially collected over phone.

Information about promotional result

The result of this study will be published in various social media, websites, conference, discussion, and reviewed journals.

Participant's fees

There is no stimulus and remuneration for participation in this study.

Source of funding to manage research

The cost of this research will be spent entirely by researchers own funds. This study will be done in small areas and no money come from external source.

Information about withdrawal from participation

Despite your consent, you can withdraw your participation at any time without giving any explanation to the researcher.

Contact address with the researcher

If you have any question about the research, you can ask me now or latter. If you wish to ask question later, you may contact any of following: Bethi Akther, Bachelor of Science in Occupational Therapy, Department of Occupational Therapy and Contact number 01676178332

Complaints

If there is any complaint regarding the conduct of this research project, contact with the Association of Ethics (77454645). This proposal has been reviewed by institutional Review Board (IBR), Bangladesh Health Professions Institute (BHPI), CRP, Savar, Dhaka-1343, Bangladesh, which is 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), CRP, Savar, Dhaka-1343, Bangladesh.

Participant's Withdrawal From

(Applicable only for voluntary withdrawal)

Reason for withdrawal:

……

……

……

Whether permission to previous information is used?

Yes/No

Participant's Name:

Part-2 Consent Sheet:

I have been invited to participate in the research titled "Health status and community functioning of adults with paediatric-onset Spinal Cord Injury". I have listened the previous letter or it has been read by me. There was an opportunity to ask my question about this and got a satisfactory answer to the all question. I voluntarily agree to be participated in this study.

Participant Name:

Date: …….

Researcher and consenting person statement:

I have read the participant's information from to the participant and according to my maximum capacity; the participants understand that the following topics will be done:

1) All the information will be used in the research work
2) Information will be totally confidential
3) Participant's name and identity will not be published

I am sure that the participant has been given the opportunity to ask questions about this topic and accurate answer to these questions has been given as per my maximum capacity. I am convinced that no person has been compelled to give consent. He or she has freely or voluntarily agreed

A copy of participant's information and consent sheet has read to the participant

Researcher Name:

Researcher signature: Date: ……

Appendix B: Information sheet and consent form [Bengali Version]

বাংলাদেশ হেলথ্ প্রফেশন্স ইনষ্টিটিউট (বিএইচপিআই)
অকুপেশনাল থেরাপি বিভাগ
সিআরপি- চাপাইন, সাভার, ঢাকা-১৩৪৩. টেলি: ০২-৭৭৪৫৪৬৪-৫,৭৭৪১৪০৪, ফ্যাক্স: ০২-৭৭৪৫০৬

অংশগ্রহণকারীদের তথ্য এবং সম্মতিপত্র

গবেষনার বিষয়ঃ শিশু অবস্থায় মেরুরজ্জুতে আঘাতপ্রাপ্ত প্রাপ্তবয়স্ক ব্যাক্তিদের স্বাস্থ্য এবং কমিউনিটিতে অংশগ্রহনের অবস্থা

গবেষক: বিথী আক্তার, বি.এস.সি ইন অকুপেশনাল থেরাপি (৪র্থ বর্ষ), সেশন: ২০১৬-২০১৭ ইং, বাংলাদেশ হেলথ্ প্রফেশন্স ইনস্টিটিউট (বিএইচপিআই), সাভার, ঢাকা- ১৩৪৩

তত্ত্বাবধায়ক: আরিফা জাহান ইমা, প্রভাষক, অকুপেশনাল থেরাপি বিভাগ,

বাংলাদেশ হেলথ প্রফেশন্স ইনস্টিটিউট।

পর্ব-১ তথ্যপত্র:

আমি বিথি আক্তার, ঢাকা বিশ্ববিদ্যালয়ে চিকিৎসা অনুষদের অধীনে বাংলাদেশ হেলথ প্রফেশনস ইনস্টিটিউটে বি.এস.সি.ইন অকুপেশনাল থেরাপি বিভাগে ৪র্থ বর্ষের ছাত্রী হিসেবে স্নাতক শিক্ষাকার্যক্রম (২০১৬-২০১৭ ইং) সেশনে অধ্যয়নরত আছি। বিএইচপিআই থেকে অকুপেশনাল থেরাপি বি.এস.সি শিক্ষাকার্যক্রমটি সম্পন্ন করার জন্য একটি গবেষনা প্রকল্প পরিচালনা করা বাধ্যতামূলক। এই গবেষণা প্রকল্পটি অকুপেশনাল থেরাপি বিভাগের প্রভাষক, আরিফা জাহান ইমা এর তত্ত্বাবধায়নে সম্পন্ন করা হবে। এই অংশগ্রহনকারী তথ্যপত্রের মাধ্যমে গবেষণার প্রকল্পটির উদ্দেশ্য, উপাত্ত সংগহের প্রণালী ও গবেষণাটির সাথে সংশ্লিস্ট বিষয় কিভাবে রক্ষিত হবে তা বিস্তারিত ভাবে আপনার কাছে 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 আরো বেশি জানার প্রয়োজন হয়, তবে নির্দ্বিধায় প্রশ্ন করতে পারেন।

গবেষনার প্রেক্ষাপট ও উদ্দেশ্য:

এই গবেষণাতে শিশু অবস্থায় মেরুরজ্জুতে আঘাতপ্রাপ্ত হয়ে বর্তমানে প্রাপ্তবয়স্ক ব্যাক্তিদের অন্তর্ভুক্ত হবার জন্য আমন্ত্রণ জানানো হবে, এর জন্য আপনাকেও উক্ত গবেষণা প্রকল্পে অংশগ্রহণের জন্য আমন্ত্রণ জানানো হলো।এই গবেষণায় আপনার উপলব্ধির অবস্থা সম্পর্কে জানার জন্য আপনাকে গবেষণায় অংশগ্রহণের জন্য আমন্ত্রণ জানানো হলো। আপনার তথ্যসমূহ আপনার উপরোক্ত অবস্থা সম্পর্কে ধারনা দিতে সাহায্য করবে। গবেষণাটির সাধারণ উদ্দেশ্য হল : " শিশু অবস্থায় মেরুরজ্জুতে আঘাতপ্রাপ্ত প্রাপ্তবয়স্ক ব্যাক্তিদের স্বাস্থ্য এবং কমিউনিটিতে অংশগ্রহণের অবস্থা তদন্ত করা। হাসপাতালে ভর্তি ব্যক্তিদের মধ্যে উপলব্ধির অবস্থা তদন্ত করা। আপনার কার্যকরী অংশগ্রহণ গবেষণার উদ্দেশ্য পূরণে সহায়তা করবে বলে আমরা আশাবাদী।

এই গবেষনা কর্মটিতে অংশগ্রহনের সাথে সম্পৃক্ত বিষয়সমূহ কি সে সম্পর্কে জানা যাক

আপনার থেকে অনুমতিপত্রে স্বাক্ষর নেবার আগে, এই অংশগ্রহনকারী 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 যদি সাক্ষর জ্ঞান সম্পন্ন না হন বা অন্য কোন কারনে স্বাক্ষর প্রদানে ব্যর্থ হন, সেক্ষেত্রে আপনার কাছ থেকে একজন স্বাক্ষীর উপস্থিতিতে বৃদ্ধাঙ্গুলির ছাপ সম্মতি পত্রে নেওয়া 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 স্বত্বেও যে কোন সময় গবেষককে কোন ব্যাখ্যা প্রদান করা ছাড়াই নিজের অংশগ্রহন প্রত্যাহার করতে পারবেন।

অংশগ্রহনের সুবিধা ও ঝুঁকিসমূহ কি?

গবেষনা প্রকল্পটিতে অংশগ্রহনের জন্য আপনি সরাসরি কোন সুবিধা পাবেন না। এই গবেষণায় অংশগ্রহনে আপনার দৈনন্দিন কাজে সাময়িক অসুবিধার কারন হতে পারে। তবে আমরা আশাবাদী যে, এই গবেষনার ফলাফল থেকে প্রাপ্ত উপকারীতা এই অসুবিধাকে অতিক্রম করবে। যে সমস্ত প্রশ্নের মাধ্যমে আপনার পরিচয় সর্ম্পকে অন্যরা জানতে পারে, সেই বিষয়ে উদ্বিগ্ন না হবার জন্য অনুরোধ করা হচ্ছে। অংশগ্রহণকারীর নাম, ঠিকানা উপাত্ত বিশ্লেষণের সফটওয়্যারে উল্লেখ না করে পরিচয় উন্মুক্ত হবার ঝুঁকি কমানো হবে।

তথ্যের গোপনীয়তা কি নিশ্চিত থাকবে?

এই সম্মতিপত্রে স্বাক্ষর করার মধ্য দিয়ে, আপনি এই গবেষনা প্রকল্পে অধ্যয়নরত গবেষনা কর্মীকে আপনার ব্যক্তিগত তথ্য সংগ্রহ ও ব্যবহার করার অনুমতি দিয়েছেন। এই গবেষনা 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 কাগজপত্র সংগ্রহ করা হবে ।

ফলাফল প্রচার সর্ম্পকিত তথ্য

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

অংশগ্রণকারীর পারিশ্রমিক

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

গবেষণা পরিচালনার 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।

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 ০১৭২১৭০০৫২৯ (বিথি আক্তার) নাম্বারে যোগাযোগ করতে পারেন।

অভিযোগ

এই গবেষনা প্রকল্প পরিচালনা প্রসঙ্গে যেকোন অভিযোগ থাকলে প্রাতিষ্ঠানিক নৈতিকতা পরিষদের সাথে এই নাম্বারে (৭৭৪৫৪৬৪-৫) যোগাযোগ করবেন। এই গবেষনা প্রকল্পটি বাংলাদেশ হেল্থ প্রফেশন্স ইনস্টিটিউট, সাভারের প্রাতিষ্ঠানিক নৈতিকতা পরিষদ থেকে সিআরপি-বিএইচপিআই/আইআরবি/১০/১৮/১২৩৪ পর্যালোচিত ও অনুমোদিত হয়েছে।

অংশগ্রহণকারীর প্রত্যাহার পত্র (শুধুমাত্র স্বেচ্ছায় প্রত্যাহারকারীর জন্য প্রযোজ্য)

অংশগ্রহনকারীর নাম: .....

প্রত্যাহার করার কারন:

.....

.....

পূর্ববর্তী তথ্য ব্যবহারের অনুমতি থাকবে কিনা?

হ্যাঁ/না ..... অংশগ্রহনকারীর নাম:..... তারিখ: .....

Appendix C: Questionnaire

SF-12 v-2 questionnaire English version

SF-12 Patient Questionnaire

Patient Initials: _____ _____ _____ Date of Birth: ___/___/___ Patkey: _____
Surgeon Name: _____ Date: _____

Examination Period: _____ Preop (1) _____ 3 Year (4)
_____ Immediate Postop (2) _____ 5 Year (5)
_____ 1 Year (3) _____ other (specify) (6)

This information will help your doctors keep track of how you feel and how well you are able to do your usual activities. Answer every question by placing a check mark on the line in front of the appropriate answer. It is not specific for arthritis. If you are unsure about how to answer a question, please give the best answer you can and make a written comment beside your answer.

1. In general, would you say your health is:
_____ Excellent (1)
_____ Very Good (2)
_____ Good (3)
_____ Fair (4)
_____ Poor (5)

The following two questions are about activities you might do during a typical day. Does YOUR HEALTH NOW LIMIT YOU in these activities? If so, how much?

2. MODERATE ACTIVITIES, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf:
_____ Yes, Limited A Lot (1)
_____ Yes, Limited A Little (2)
_____ No, Not Limited At All (3)

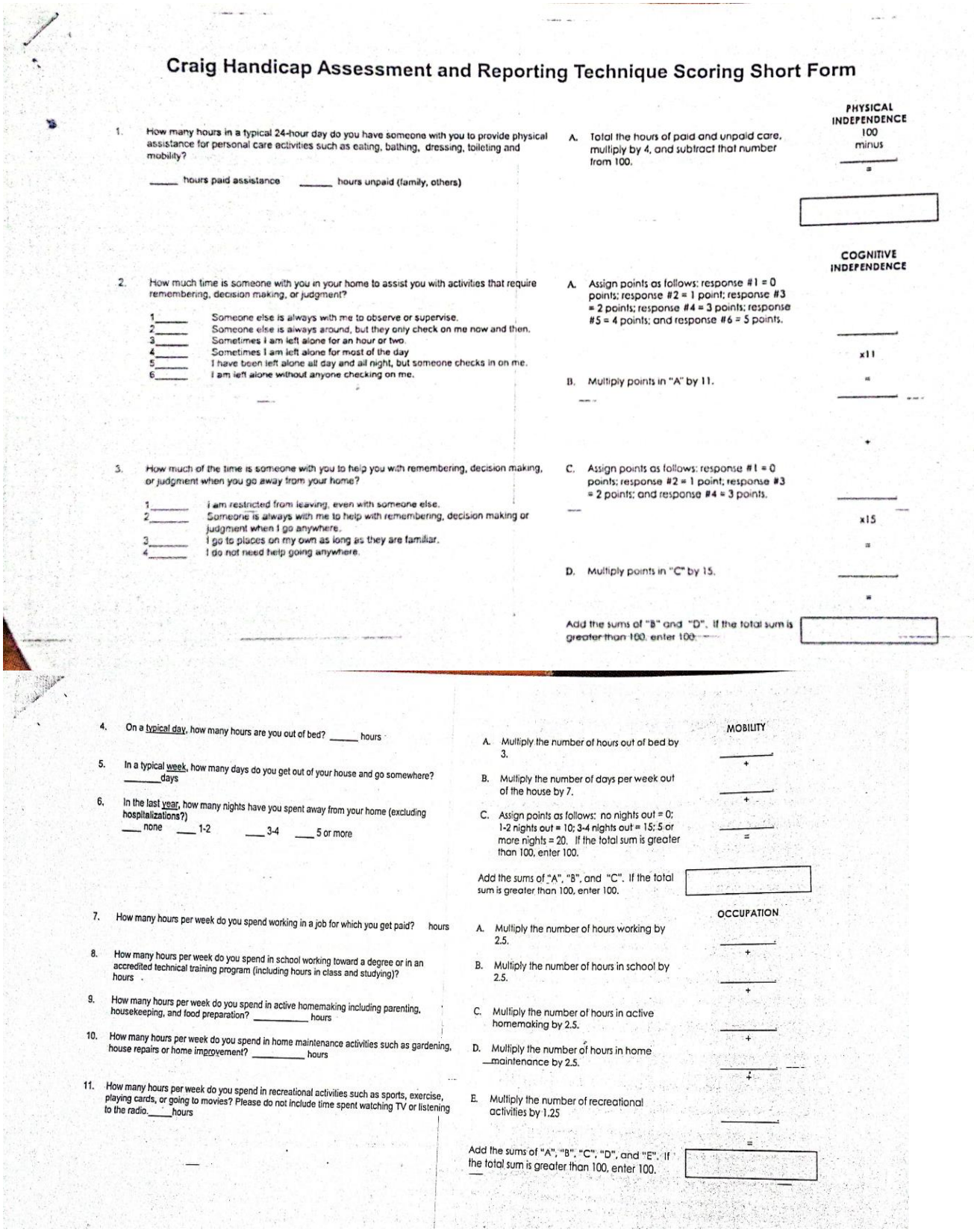
3. Climbing SEVERAL flights of stairs:
_____ Yes, Limited A Lot (1)
_____ Yes, Limited A Little (2)
_____ No, Not Limited At All (3)

During the PAST 4 WEEKS have you had any of the following problems with your work or other regular activities AS A RESULT OF YOUR PHYSICAL HEALTH?

4. ACCOMPLISHED LESS than you would like:
_____ Yes (1)
_____ No (2)

5. Were limited in the KIND of work or other activities:
_____ Yes (1)
_____ No (2)

CHART questionnaire English version



Craig Handicap Assessment and Reporting Technique Scoring Short Form

1. How many hours in a typical 24-hour day do you have someone with you to provide physical assistance for personal care activities such as eating, bathing, dressing, toileting and mobility?

   _____ hours paid assistance _____ hours unpaid (family, others)

   A. Total the hours of paid and unpaid care, multiply by 4, and subtract that number from 100.

PHYSICAL INDEPENDENCE
100
minus
_____
=
[ ]

COGNITIVE INDEPENDENCE

2. How much time is someone with you in your home to assist you with activities that require remembering, decision making, or judgment?

   1_____ Someone else is always with me to observe or supervise.
   2_____ Someone else is always around, but they only check on me now and then.
   3_____ Sometimes I am left alone for an hour or two.
   4_____ Sometimes I am left alone for most of the day
   5_____ I have been left alone all day and all night, but someone checks in on me.
   6_____ I am left alone without anyone checking on me.

   A. Assign points as follows: response #1 = 0 points; response #2 = 1 point; response #3 = 2 points; response #4 = 3 points; response #5 = 4 points; and response #6 = 5 points.

   _____
   x11
   =
   _____

   B. Multiply points in "A" by 11.

3. How much of the time is someone with you to help you with remembering, decision making, or judgment when you go away from your home?

   1_____ I am restricted from leaving, even with someone else.
   2_____ Someone is always with me to help with remembering, decision making or judgment when I go anywhere.
   3_____ I go to places on my own as long as they are familiar.
   4_____ I do not need help going anywhere.

   C. Assign points as follows: response #1 = 0 points; response #2 = 1 point; response #3 = 2 points; and response #4 = 3 points.

   _____
   x15
   =
   _____

   D. Multiply points in "C" by 15.

   =

   Add the sums of "B" and "D". If the total sum is greater than 100, enter 100.
   [ ]

4. On a typical day, how many hours are you out of bed? _____ hours

5. In a typical week, how many days do you get out of your house and go somewhere? _____days

6. In the last year, how many nights have you spent away from your home (excluding hospitalizations?)
   ___ none ___ 1-2 ___ 3-4 ___ 5 or more

MOBILITY

   A. Multiply the number of hours out of bed by 3.

   _____
   +

   B. Multiply the number of days per week out of the house by 7.

   _____
   +

   C. Assign points as follows: no nights out = 0; 1-2 nights out = 10; 3-4 nights out = 15; 5 or more nights = 20. If the total sum is greater than 100, enter 100.

   _____
   =

   Add the sums of "A", "B", and "C". If the total sum is greater than 100, enter 100.
   [ ]

7. How many hours per week do you spend working in a job for which you get paid? hours

8. How many hours per week do you spend in school working toward a degree or in an accredited technical training program (including hours in class and studying)? hours

9. How many hours per week do you spend in active homemaking including parenting, housekeeping, and food preparation? _____ hours

10. How many hours per week do you spend in home maintenance activities such as gardening, house repairs or home improvement? _____ hours

11. How many hours per week do you spend in recreational activities such as sports, exercise, playing cards, or going to movies? Please do not include time spent watching TV or listening to the radio._____hours

OCCUPATION

   A. Multiply the number of hours working by 2.5.

   _____
   +

   B. Multiply the number of hours in school by 2.5.

   _____
   +

   C. Multiply the number of hours in active homemaking by 2.5.

   _____
   +

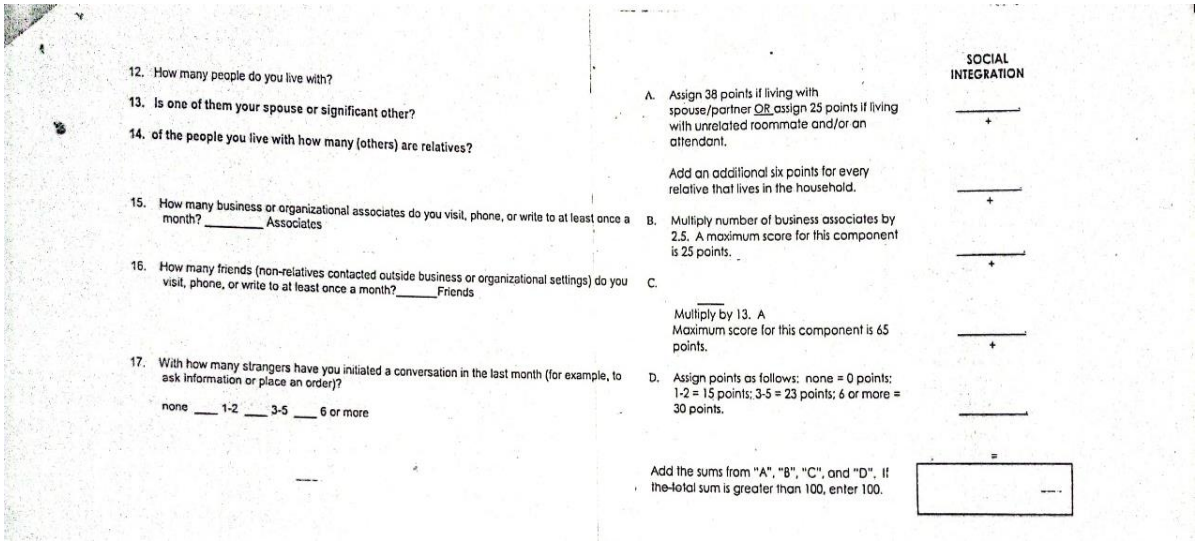
   D. Multiply the number of hours in home maintenance by 2.5.

   _____
   +

   E. Multiply the number of recreational activities by 1.25

   _____
   =

   Add the sums of "A", "B", "C", "D", and "E". If the total sum is greater than 100, enter 100.
   [ ]



12. How many people do you live with?

13. Is one of them your spouse or significant other?

14. of the people you live with how many (others) are relatives?

15. How many business or organizational associates do you visit, phone, or write to at least once a month? _____ Associates

16. How many friends (non-relatives contacted outside business or organizational settings) do you visit, phone, or write to at least once a month?_____Friends

17. With how many strangers have you initiated a conversation in the last month (for example, to ask information or place an order)?

none ___ 1-2 ___ 3-5 ___ 6 or more

SOCIAL INTEGRATION

A. Assign 38 points if living with spouse/partner OR assign 25 points if living with unrelated roommate and/or an attendant.

Add an additional six points for every relative that lives in the household.

B. Multiply number of business associates by 2.5. A maximum score for this component is 25 points.

C. ___

Multiply by 13. A Maximum score for this component is 65 points.

D. Assign points as follows: none = 0 points; 1-2 = 15 points; 3-5 = 23 points; 6 or more = 30 points.

Add the sums from "A", "B", "C", and "D". If the total sum is greater than 100, enter 100.

SF-12 Bangla version

Bengali SF 12v2 Health Survey

এই জরিপে আপনার স্বাস্থ্য সম্পর্কে আপনার দৃষ্টিভঙ্গি জানতে চাওয়া হয়েছে। আপনি কেমন বোধ করেন এবং আপনার স্বাভাবিক কার্যক্রম কতটা ভালোভাবে করতে পারেন এই জরিপ তা বুঝতে সাহায্য করবে।
নিচের প্রত্যেকটি প্রশ্নের জন্য একটি করে টিক চিহ্ন দিন, যেটি আপনার জন্য সবচেয়ে সঠিক উত্তর বলে আপনি মনে করেন।

১) সব মিলিয়ে আপনি কি বলবেন আপনার স্বাস্থ্য কেমন?
০ চমৎকার ০ খুব ভালো ০ ভালো ০ মোটামুটি ০ খারাপ

২) নিচের প্রশ্নগুলো আপনি প্রতিদিন যে কাজগুলো করতে পারেন সে সম্পর্কিত । আপনার স্বাস্থ্য কি বর্তমানে সেসব কর্মকাণ্ডে ব্যাঘাত ঘটায় ? ঘটালে কতটুকু?

ক) মাঝারি কাজ যেমনঃ একটি টেবিল সরানো, মাঝারি সাইজের পানি ভর্তি একটি বালতি সরানো, ভ্যাকুয়াম ক্লিনার ঠেলা, বোলিং বা গলফ খেলা
০ হ্যাঁ, অনেকটা বাধাগ্রস্ত করে
০ হ্যাঁ, কিছু বাধাগ্রস্ত করে
০ না, মোটেই বাধাগ্রস্ত করে না

খ) বেশ কয়েক ধাপ সিঁড়ি বেয়ে ওঠা
০ হ্যাঁ, অনেকটা বাধাগ্রস্ত করে
০ হ্যাঁ, কিছু বাধাগ্রস্ত করে
০ না, মোটেই বাধাগ্রস্ত করে না

৩) গত চার সপ্তাহে শারীরিক কারণে আপনার কাজ বা অন্যান্য দৈনন্দিন কর্মকাণ্ডের জন্য নিচের সমস্যাগুলো কত সময় ধরে হয়েছিল?

ক) যতটা কাজ করতে চেয়েছিলেন তার চেয়ে কম করতে পেরেছেন
০ সবসময় ০ বেশিরভাগ সময় ০ কিছু সময় ০ খুব অল্প সময় ০ কখনই না।
খ) কোনো কোনো কাজে সীমাবদ্ধতা ছিল
০ সবসময় ০ বেশিরভাগ সময় ০ কিছু সময় ০ খুব অল্প সময় ০ কখনই না।

৪) গত চার সপ্তাহে আবেগজনিত সমস্যা, যেমনঃ বিষণ্ন বা দুশ্চিন্তাগ্রস্থ থাকার কারণে আপনার কাজ বা অন্যান্য দৈনন্দিন কর্মকাণ্ডের জন্য নিচের সমস্যাগুলো কত সময় ধরে হয়েছিল?

ক) যতটা কাজ করতে চেয়েছিলেন তার চেয়ে কম করতে পেরেছেন

০ সবসময় ০ বেশিরভাগ সময় ০ কিছু সময় ০ খুব অল্প সময় ০ কখনই না।

খ) যেভাবে মনোযোগের সাথে কাজগুলো করেন তারচেয়ে কম মনোযোগী ছিলেন

০ সবসময় ০ বেশিরভাগ সময় ০ কিছু সময় ০ খুব অল্প সময় ০ কখনই না।

৫) গত চার সপ্তাহে ব্যথাজনিত কারণে ঘরের এবং ঘরের বাইরের স্বাভাবিক কাজগুলো করতে আপনার কতটা সমস্যা হয়েছিল ?

০ একেবারেই না ০ খুব অল্প ০ মোটামুটি ০ অনেকটা ০ খুব বেশী

৬) গত চার সপ্তাহে আপনার সার্বিক অবস্থা কেমন ছিল এবং আপনি কেমন বোধ করেছিলেন, এই প্রশ্নগুলো সে সম্পর্কিত।
প্রত্যেকটি প্রশ্নের জন্য অনুগ্রহ করে একটি উত্তর নির্ধারণ করুন যা আপনার অনুভূতির সবচেয়ে কাছাকাছি ।

ক) গত চার সপ্তাহের কতটা সময় আপনি স্থির এবং শান্তিপূর্ণ অনুভব করেছিলেন?

০ সবসময় ০ বেশিরভাগ সময় ০ কিছু সময় ০ খুব অল্প সময় ০ কখনই না।

খ) আপনি কি অনেক উদ্যোমী বা কর্মশক্তিসম্পন্ন ছিলেন?

০ সবসময় ০ বেশিরভাগ সময় ০ কিছু সময় ০ খুব অল্প সময় ০ কখনই না।

গ) আপনি কি মনমরা এবং হতাশ বোধ করেছিলেন?

০ সবসময় ০ বেশিরভাগ সময় ০ কিছু সময় ০ খুব অল্প সময় ০ কখনই না।

৭) শারীরিক এবং আবেগজনিত সমস্যা, যেমনঃ বিষণ্ন বা দুশ্চিন্তাগ্রস্থ থাকার কারনে গত চার সপ্তাহের কতটা সময় সামাজিক কর্মকাণ্ড (যেমনঃ বন্ধুবান্ধব বা আত্মীয়স্বজন ইত্যাদির সাথে দেখা করা) বিঘ্নিত হয়েছে ?

০ সবসময় ০ বেশিরভাগ সময় ০ কিছু সময় ০ খুব অল্প সময় ০ কখনই না।

প্রশ্নগুলো পুরণ করার জন্য ধন্যবাদ।

CHART-Bangla questionnaire

ক্রেগ হ্যান্ডিক্যাপ অ্যাসেসমেন্ট এবং রিপোর্টিং টেকনিক স্কোরিং শর্ট ফর্ম

১। একটি সাধারণ ২৪-ঘন্টা দিনে কত ঘন্টা আপনার সাথে কেউ থাকে ব্যক্তিগত যত্নের কার্যক্রমগুলো করার জন্য? যেমনঃ খাওয়া, স্নান, ড্রেসিং, টয়লেটিং এবং চলাফেরার জন্য শারীরিক সহায়তা প্রদান।

_____ঘন্টা পরিশোধ করা সহায়তা _____ঘন্টা (অবৈতনিক) (পরিবার, অন্যান্য)

ক। পেইড এবং আনপেইড যত্নের মোট ঘন্টা, ৪ দ্বারা গুণ করুন এবং সেই সংখ্যাটি ১০০ থেকে বিয়োগ করুন

ফিজিক্যাল ইন্ডিপেন্ডেন্স (শারীরিক সক্ষমতা)

১০০ বিয়োগ

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২। মনে রাখা, সিদ্ধান্ত নেওয়া বা বিচার বিবেচনার প্রয়োজন হয় এমন কাজগুলিতে আপনাকে সহায়তা করার জন্য আপনার বাড়িতে আপনার সাথে কেউ কত সময় থাকে?

i. _____পর্যবেক্ষন বা তদারকি করার জন্য অন্য কেউ সবসময় আমার সাথে থাকে।
ii. _____অন্য কেউ সর্বদা আশেপাশে থাকে, কিন্তু তারা কেবল আমাকেই তদারকি করেন।
iii. _____মাঝে মাঝে আমি এক বা দুই ঘন্টা একা থাকি।
iv. _____কখনও কখনও আমি দিনের বেশিরভাগ সময় একা থাকি ।
v. _____আমি সারা দিন এবং সারা রাত একা থাকি, কিন্তু কেউ আমাকে চেক ইন করে।
vi. _____কেউ আমাকে তদারকি করে না, আমি একাই থাকি ।

কগনিটিভ ইন্ডিপেন্ডেন্স (জ্ঞান ভিত্তিক সক্ষমতা)

কগনিটিভ ইন্ডিপেন্ডেন্স (জ্ঞান ভিত্তিক সক্ষমতা)

ক। নিম্নরূপ পয়েন্টগুলি বরাদ্দ করুন: উত্তর ১ = ০ পয়েন্ট

উত্তর ২ = ১ পয়েন্ট

উত্তর ৩ = ২ পয়েন্ট

উত্তর ৪ = ৩ পয়েন্ট

উত্তর ৫ = ৪ পয়েন্ট

উত্তর ৬ = 5 পয়েন্ট

খ। ১১ দ্বারা "ক" এর পয়েন্ট গুণ করুন।

X ১১

৩। আপনি আপনার বাড়ির কাছ থেকে দূরে যাবার সময় কোন কিছু স্মরণ করতে, সিদ্ধান্ত নিতে বা কিছু বিচার বিবেচনা করতে আপনাকে সাহায্য করার জন্য আপনার সাথে কত সময় কেউ থাকেন?

i. _____ আমি অন্য কারো সাথেও বাসা থেকে দূরে কোথাও যেতে পারিনা ।
ii. _____ কোন কিছু স্মরণ করতে, সিদ্ধান্ত নিতে বা কিছু বিচার বিবেচনা করতে আমাকে সাহায্য করার জন্য সবসময়ই আমার সাথে কেউ থাকেন ।
iii. _____ আমি নিজের পরিচিত জায়গায় একাই যাই।
iv. _____ আমার কোথাও যেতে সাহায্য প্রয়োজন হয় না।

গ। নিম্নরূপ পয়েন্টগুলি বরাদ্দ করুন:

উত্তর ১ = ০ পয়েন্ট

কগনিটিভ ইন্ডিপেন্ডেন্স (জ্ঞান ভিত্তিক সক্ষমতা)

ক। নিম্নরূপ পয়েন্টগুলি বরাদ্দ করুন: উত্তর ১ = 0 পয়েন্ট

উত্তর ২ = ১ পয়েন্ট

উত্তর ৩ = ২ পয়েন্ট

উত্তর ৪ = ৩ পয়েন্ট

উত্তর ৫ = ৪ পয়েন্ট

উত্তর ৬ = 5 পয়েন্ট

খ। ১১ দ্বারা "ক" এর পয়েন্ট গুণ করুন। X ১১

৩। আপনি আপনার বাড়ির কাছ থেকে দূরে যাবার সময় কোন কিছু স্মরণ করতে, সিদ্ধান্ত নিতে বা কিছু বিচার বিবেচনা করতে আপনাকে সাহায্য করার জন্য আপনার সাথে কত সময় কেউ থাকেন?

i. _____ আমি অন্য কারো সাথেও বাসা থেকে দূরে কোথাও যেতে পারিনা ।
ii. _____ কোন কিছু স্মরণ করতে, সিদ্ধান্ত নিতে বা কিছু বিচার বিবেচনা করতে আমাকে সাহায্য করার জন্য সবসময়ই আমার সাথে কেউ থাকেন ।
iii. _____ আমি নিজের পরিচিত জায়গায় একাই যাই।
iv. _____ আমার কোথাও যেতে সাহায্য প্রয়োজন হয় না।

গ। নিম্নরূপ পয়েন্টগুলি বরাদ্দ করুন:

উত্তর ১ = 0 পয়েন্ট

গ। নিম্নরূপ পয়েন্টগুলি বরাদ্দ করুন:

উত্তর ১ = ০ পয়েন্ট

উত্তর ২ = ১ পয়েন্ট

উত্তর ৩ = ২ পয়েন্ট

উত্তর ৪ = ৩ পয়েন্ট

ঘ। ১৫ দ্বারা "গ" এর পয়েন্ট গুণ করুন। X ১৫

"গ" এবং "ঘ" এর নম্বর যোগ করুন। যদি মোট যোগফল ১০০ অপেক্ষা বেশি হয় তবে, ১০০ লিখুন।

মোবিলিটি

৪। একটি সাধারণ দিনে আপনি কত ঘন্টা বিছানা থেকে বাহিরে থাকেন?

..... ঘন্টা

ক। বিছানা থেকে বাহিরে থাকার ঘন্টা গুণ ৩

৫। একটি সাধারণ সপ্তাহে, আপনি বাড়ির বাইরে কত দিন থাকেন এবং কোথাও যান?

_____ দিন

খ। প্রতি সপ্তাহে বাড়ির বাইরে থাকা দিনের সংখ্যা গুণ ৭ ।

৬। গত বছরে, আপনি আপনার বাড়ি থেকে কত রাত দূরে কাটিয়েছেন (হাসপাতালে ভর্তি ব্যতীত?)

..... একদিনও না

..... ১-২ দিন

..... ৩-৪ দিন

..... ৫ দিন বা তার বেশি

গ। নিম্নরূপ পয়েন্টগুলো বরাদ্দ করুন:

এক রাতও বাহিরে থাকেন নি = ০

১-২ রাত বাহিরে = ১০

৩-৪ রাত বাহিরে = ১৫

৫ বা তার বেশি রাত বাহিরে = ২০

মোট যোগফল ১০০ এর বেশি হলে, ১০০ লিখুন।

"ক", "খ", এবং "গ" এর যোগফল লিখুন। মোট যোগফল ১০০ এর বেশি হলে, ১০০ লিখুন।

৭। আপনি প্রতি সপ্তাহে কত ঘন্টা কাজ করেন যে কাজের জন্য আপনি বেতন পান?

..... ঘন্টা

৮। আপনি প্রতি সপ্তাহে কত ঘন্টা স্কুলে একটি ডিগ্রি বা একটি স্বীকৃত প্রযুক্তিগত প্রশিক্ষণ প্রোগ্রামে (ক্লাস এবং অধ্যয়নের সময় সহ) কাজ করেন?

..... ঘন্টা

৯। প্রতি সপ্তাহে কত ঘন্টা আপনি প্যারেন্টিং, গৃহস্থালি, এবং খাদ্য প্রস্তুত সহ সক্রিয়ভাবে গৃহস্থলির কাজে ব্যয় করেন?

..... ঘন্টা

১০। আপনি প্রতি সপ্তাহে কত ঘন্টা বাড়ির রক্ষণাবেক্ষণের কাজে ব্যয় করেন? (যেমন বাগান করা, বাড়ি মেরামত বা বাড়ির উন্নতি করা)

১১। আপনি প্রতি সপ্তাহে কত ঘন্টা বিনোদনমূলক ক্রিয়াকলাপ যেমন (খেলাধুলা, ব্যায়াম, তাস খেলা বা সিনেমা দেখতে ব্যয় করেন? (অনুগ্রহ করে টিভি দেখার বা রেডিও শোনার সময় কাটানো সময় অন্তর্ভুক্ত করবেন না) ..... ঘন্টা

পেশা

ক। কাজের সময় ২.৫ দ্বারা গুণ করুন _____

খ। স্কুলের সময় ২.৫ দ্বারা গুণ করুন _____

গ। গৃহস্থালির কাজের সময় ২.৫ দ্বারা গুণ করুন _____

ঘ। বাড়ির রক্ষণাবেক্ষণের সময়কে ২.৫ দ্বারা গুণ করুন _____

ঙ। বিনোদনের কাজের সংখ্যা ১.২৫ গুণ করুন _____

"ক", "খ", "গ", "ঘ", এবং "ঙ" এর গুনফল যোগ করুন।

মোট যোগফল 100 এর বেশি হলে, 100 লিখুন। [ ]

১২। আপনি কত জন মানুষের সাথে বাস করেন?

.....।

১৩। তাদের মধ্যে একজন কি আপনার পত্নী নাকি উল্লেখযোগ্য অন্য কেউ?

১৪। আপনি যাদের সাথে থাকেন তাদের মধ্যে কতজন আপনার আত্মীয়?

.....

১৫। আপনি মাসে অন্তত একবার কতজন ব্যবসায়িক বা সাংগঠনিক সহযোগীদের সাথে দেখা করেন, ফোন করেন বা চিঠি দেন?

.....

১৬। আপনি কতজন বন্ধু (অনাত্মীয়র ব্যবসায়িক বা সাংগঠনিক সেটিংসের বাইরে যোগাযোগ করেছেন) মাসে অন্তত একবার দেখা করেন, ফোন করেন বা চিঠি লিখেন?

.....

১৭। গত মাসে কতজন অপরিচিত ব্যক্তির সাথে আপনি একটি কথোপকথন নিজে থেকে শুরু করেছেন (উদাহরণস্বরূপ, তথ্য জিজ্ঞাসা করতে বা অর্ডার দেওয়ার জন্য)?

..... একজনও না

..... ১-২ জন

..... ৩-৫ জন

..... ৬ দিন বা তার বেশি

১৮। গত বছরে আপনার পরিবারের সকল সদস্যের সম্মিলিত বার্ষিক আয় প্রায় কত ছিল? (মজুরি এবং উপার্জন, অক্ষমতা সুবিধা, পেনশন এবং অবসরকালীন আয়, আদালতের নিষ্পত্তি থেকে আয়, বিনিয়োগ এবং ট্রাস্ট তহবিল, শিশু সহায়তা এবং ভরণপোষণ, আত্মীয়দের কাছ থেকে অবদান এবং অন্য কোনও উত্স সহ সমস্ত উত্স বিবেচনা করুন।)

ক ২৫,০০০ এর কম - যদি না হয় জিজ্ঞাসা করুন ঙ; যদি হ্যাঁ হয় জিজ্ঞাসা করুন খ ।

খ. ২০,০০০ এর কম – যদি যদি না হয় কোড ২২৫০০। যদি হ্যাঁ হয় গ জিজ্ঞাসা করুন ।

গ. ১৫,০০০ এর কম – যদি না হয় কোড ১৭,৫০০। কোড না থাকে; যদি হ্যাঁ হয় গ জিজ্ঞাসা করুন ।

ঘ। ১০,০০০ এর কম - যদি না হয় কোড ১২,৫০০; যদি হ্যাঁ হয় কোড ৫০০০।

ঙ। ৩৫,০০০ এর কম- যদি না হয় চ জিজ্ঞাসা করুন; যদি হ্যাঁ হয় কোড ৩০,০০০।

চ।৫০,০০০ এর কম - যদি না হয় ছ জিজ্ঞাসা করুন, যদি হ্যাঁ হয় কোড ৪২,৫০০।

জ।৭৫,০০০ এর কম - যদি না হয় ঝ জিজ্ঞাসা করুন; যদি হ্যাঁ হয় কোড ৬২৫০০।

ঝ। ৭৫,০০০ বা তার বেশি - কোড ৮০,০০০।

১৯। চিকিৎসা সেবার খরচের জন্য আপনি গত বছর আনুমানিক কত টাকা দিয়েছিলেন? (আপনার বা আপনার পরিবারের পরিবারের সদস্যদের দ্বারা প্রদত্ত যেকোন পরিমাণ বিবেচনা করুন এবং বীমা বা সুবিধার দ্বারা পরিশোধ করা গ)

ক। ১০০০ এর কম - "না" হলে খ জিজ্ঞাসা করুন। যদি "হ্যাঁ" হয় কোড ৫০০।

খ। ২৫০০ এর কম - "না" হলে গ জিজ্ঞাসা করুন । যদি "হ্যাঁ" হয় কোড ১৭৫০।

গ। ৫০০০ এর কম - "না" হলে ঘ জিজ্ঞাসা করুন । যদি "হ্যাঁ" হয় কোড ৩৭৫০।

ঘ। ১০০০০ এর কম - "না" হলে ঙ জিজ্ঞাসা করুন । যদি "হ্যাঁ" হয় কোড ৭৫০০।

Socio-demographic Information English

Patient's ID No: ……. Patient's name: ……

Sex: …….. Age in this year: …… Date of Injury: …….

Type of Injury: …… Year of rehabilitation: ……

Previous work: …… Current work: ……

District: …… Contact number: ……..……

Date of data collection: …….

জনসংখ্যা সংক্রান্ত তথ্য

রোগীর আইডি নম্বর: ……..

রোগীর নাম: …… লিঙ্গ: …….এই বছরে বয়স: ……

আঘাতের তারিখ:…… আঘাতের প্রকারঃ ……

পুনর্বাসনের বছর: …… পূর্ববর্তী কাজ: …… বর্তমান কাজ: …….. জেলা: …… যোগাযোগ নম্বর: …… তথ্য সংগ্রহের তারিখ: …….

Appendix D : Supervision record sheet

Bangladesh Health Professions Institute
Department of Occupational Therapy
4th Year B. Sc in Occupational Therapy
OT 401 Research Project

Thesis Supervisor- Student Contact; face to face or electronic and guidance record

Title of thesis: Health and Occupation status of adults with Pediatric Onset Spinal Cord Injury.

Name of student: Bethi Akther. Roll: 04

Name and designation of thesis supervisor: Arifa Jahan Ema, Lecturer
Department of Occupational Therapy, (BHPI), CRP, Savar.

Appointment No	Date	Place	Topic of discussion	Duration (Minutes/ Hours)	Comments of student	Student's signature	Thesis supervisor signature
1	02.11.21	BHPI Library	Supervision guideline, Literature review, IRB Application.	about 1 hour	Helpful Information to work ahead.	Bethi Akther.	AG 02.11.21
2	08.11.21	BHPI Room no: 208	IRB application form check, Questionnaire Bangla, Participant list	2 hour	IRB checked, Questionnaire was translated in Bangla	Bethi Akther.	AG 08.11.21
3	17.11.21	OT Dept. waiting room.	Participant list, Questionnaire check, Author contact, Lit review check.	1:30 hour	I got excellent guidlines about all the topics.	Bethi Akther.	AG 17.11.21
4	22.11.21	BHPI Building Entrance	Author communication, Participant Database	5 min	I got ma'am in my urgent query time & guided well.	Bethi Akther.	AG 22.11.21
5	04.11.21	BHPI Room no: 208	Overall guideline by date to date.	1 hour.	Points noted for the month of november.	Bethi Akther.	AG 04.11.21
6	04.12.21	BHPI Library	Data collection guideline, Questionnaire discussion.	59 min. 1 hour	Got structured guideline about data collection.	Bethi Akther.	AG 04.12.21
7	11.12.21	BHPI Office	Questionnaire issue solve.	30 min	have to check poverty level, chart.	Bethi Akther.	AG 11.12.21
8	14.12.21	BHPI Office	Question poverty level, population response.	30 min	Problem clear.	Bethi Akther.	AG 14.12.21
9	09.01.22	BHPI Office	Data management, Lit-Review, SPSS, Data collection.	1.5hour	got work timeline ahead.	Bethi Akther.	AG 09.01.22
10	10.01.22	-	spss, data input and variable.	30 min.	cleared the problem.	Bethi Akther.	10.1.22 AG 10.01.22
11	16.01.22	BHPI Teachers room.	Data input, method, analysis and others timeline	30min.	Got structured guideline.	Bethi Akther.	AG 16.01.22
12	18.01.22	BHPI Room 307.	Data analysis	30 min	Analysis review, recoding data.	Bethi Akther.	18.01.22
13	25.01.22	BHPI Teachers room.	SF-12 scoring & Chart analysis.	30min.	Analysis, scoring discussion	Bethi Akther.	25.1.22
14	27.01.22	BHPI Teachers room.	SF-12 scoring & analysis.	30 min.	Have to study article and reverse code data.	Bethi Akther.	

15	02.02.22	BHPI office.	CHART analysis, SF-12 Analysis discussion	40 min.	CHART analysis clearc, SF-12 scale analysis systen	Bethi Akther.	02.02.22
16	08.02.22	BHPI office.	SF-12 analysis, Result and discussion	1 hour	How to write result and analysis.	Bethi Akther.	08.02.22
17	15.02.22	BHPI office.	Took feedback ~~of~~ on Lit. Review, analysis, result. discussion.	1 hour.	Have to correct according to feedback.	Bethi Akther.	15.02.22
18	20.02.22	BHPI classroom	Thesis draft formating.	1.5 hour	Thesis draft formating guideline.	Bethi Akther.	20.02.22
19	05.03.22	BHPI office	Discussion about results of CHART Domain	30 min	Instructed to update the result chapter.	Bethi Akther.	05.03.22
20	29.03.22	BHPI office	Discussion about the result, Lit-review.	30 min	study more lit. and write properly	Bethi Akther.	29.03.22

Note:

1. Appointment number will cover at least a total of 40 hours; applicable only for face to face contact with the supervisors.
2. Students will require submitting this completed record during submission your final thesis.

21	BHPI office	03.04.22	Introduction and Lit. review discussion	30 min	Deadline for submission on 7th April 2022	Bethi Akther.	03.04.22
5	BHPI office	09.04.22	First draft feedback on Introduction. Lit review	30 min	To correct the problems on draft	Bethi Akther.	09.04.22
6	BHPI office	13.04.22	Comparing and contrasting methods.	30 min	further correction on Intro and lit reviews.	Bethi Akther.	13.04.22
7	BHPI library	17.04.22	Presentation check and feedback	3 hour	Presenting date 20th april, next meet: 19th april	Bethi Akther.	17.04.22
8	BHPI library	19.04.22	Research draft final checking.	2 hour	Presentation final draft final check.	Bethi Akther.	19.04.22
9	BHPI library	21.04.22	Presentation checking, correction	1.5 hour	Presentation and book check	Bethi Akther.	21.04.22
10							
11							
12							
13							
14							