## "Understanding Occupational Engagement and Subjective Well-being among Person with Spinal Cord Injury after Rehabilitation"



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### **Statement of Authorship**

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The ethical issues of the study has been strictly considered and protected. In case of dissemination the finding of this project for future publication, research supervisor will highly concern and it will be duly acknowledged as undergraduate thesis.

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### **List of Abbreviation**

**SWB** Subjective Well-Being

**SCI** Spinal Cord Injury

**OE** Occupational Engagement

**ADL** Activities of Daily Living

**CRP** Centre for the Rehabilitation of the Paralysed

**BHPI** Bangladesh Heath Professions Institute

**AOTA** American Occupational Therapy Association

**NSCISC** National Spinal Cord Injury Statistical Center

**PWD** Personal Well-being Index

WHO World Health Organization

#### **Abstract**

Well-being is an important part while people with SCI engage in different occupations after returning to their community. The people with SCI basically face many difficulties after their rehabilitation such as in occupational engagement. The study explores whether the occupational engagement influence their life satisfaction as well as well-being. The study attempts to know the participants understanding about their occupational engagement and subjective well-being. The data have been collected by semi-structured open ended questionnaire through in-depth interview. About thirteen participants were selected by using convenient sampling from the SCI patient list who lives in community after their rehabilitation. Data has been analyzed by Qualitative thematic analysis. From the findings of the research it is seen that, engagement in routine based household and productive work is referred to occupational engagement. Satisfaction in OE is influenced by physical & social environmental factors. Psychological, social, family and financial capabilities are the prioritized enablers to optimize well-being in daily engagement. Engaging in occupation ensures mindfulness and pleasure in living. Lack of accessibility, safety and poor social, family relationships have influences in well-being. So, from participants understanding being satisfied with productive and routine work considering the key factors (accessibility, security and bonding) are occupational engagements where psychological, social, financial and family supports are key essentials for influencing their well-being. This study will be effective to engage in their occupational life promoting life satisfaction.

Keywords: Subjective well-being, Occupational Engagement, Spinal Cord Injury

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#### 1.1 Introduction

Subjective Well-Being (SWB) refers to the way individuals perceive their life as a whole. Thus it comprises people's overall evaluation about their lives which is about life satisfaction and feelings that reflect how people are reacting on their circumstances of living (Diener et al., 2017). One of the key factors for promoting well-being lies in balancing one's daily life occupations and the nature of these occupations. Occupation refers to goal-directed activities of everyday life which may be associated to life areas such as leisure, education, or self-care (Anaby, 2010). There are five components of well-being as of: positive emotions, engagement, relationships, meaning, and accomplishment in life (Goodman et al., 2017). Subjective well-being is what people call happiness, satisfaction or pleasure.

People with Spinal Cord Injury face many obstacles when they return to the community after rehabilitation. The concept of SWB is an important outcome measure to understand the efficacy of rehabilitation (Adams et al., 2011). Spinal cord injury (SCI) has become a common problem all over the world particularly in Bangladesh. Over the time, the number of people with SCI as well as disability is increasing rapidly in Bangladesh (Islam et al., 2011). SCI cause enormous changes in people's life such as physical, psychological and social functioning which is interacted with health conditions and some factors related to personal and environmental aspects. Nowadays personal aspects include individual's health condition, physical and functional state. Environmental aspects include physical, social and attitudinal factors that can facilitate or hinder an individual's performance in daily activities (Van Leeuwen, 2012). Nevertheless, SCI imposed a significant emotional and financial burden on patients, families, and society. Resulting from this, the ability to engage in everyday activities outside and inside the home are changing and modifying such as, Engagement in work, leisure and self-care activities can decrease leading to social isolation (Barclay et al., 2015). Person with SCI also depends on factors after their rehabilitation care such as facing functioning restriction, activity limitations in daily life, challenges in physical and social environment, family support and getting occupational opportunities. That is very important to understand the impaired functioning and activity limitations that hampering to their occupational engagement as well as satisfaction of life which is inter-related with well-being. Reid (2008) defined occupational engagement as "being occupied with doing an occupation and is viewed as a powerful determinant of a person's well-being".

On the other hand, engagement in daily occupations and community participation can have a positive effect on quality of life of people with SCI and their families: providing financial security, environment for social interaction, autonomy selfesteem, confidence and independence whereas, Positive well-being occurs when people get engaged in occupations with both positive personal value and positive perceived consequences for both the individual and the society in which they live (Morris & Cox, 2017).

Individuals with SCI, it is necessary to explore common themes that they use to evaluate their life satisfaction as well as well-being. A study describes, both personal (self-esteem, confidence, independence) and external (social interaction, environment, participation) factors has been seen to have an influence on engagement, some promoting and others inhibiting (Sidlauskiene et al., 2017).

An occupation with positive value for the individual can have negative consequences and vice versa. Occupational engagement is also a fluctuating state of individual with SCI who is influenced by complex and multiple internal and external factors. The person will perceive positive or negative consequences to engage in response to social, cultural, and physical environments, which may change over time (AOTA, 2014). From the Bangladeshi perspective, it is important to conduct a study that will be helpful to understand how occupational engagement influences well-being to the person with SCI after their rehabilitation by perceiving experiences.

#### 1.2 Background of the study

In Bangladesh Spinal Cord Injury (SCI) is the common cause that people are being disabled every year. When a person is injured with spinal cord then it affects to the all aspects of his life. Spinal cord injury is a disorder that creates loss of functions, independence and physical activity in daily and social life. It also impacts in engaging and participating in various areas of everyday life (Sidlauskiene et al., 2017). There is an interesting part is that; The Centre for the Rehabilitation of the Paralysed (CRP) provides an opportunity to promote occupational engagement as well as well-being for patient with spinal cord injury. The health and rehabilitation need of SCI patient is complex in nature. Rehabilitation is a long term process and through CRP is one of major rehabilitation centre in Bangladesh. CRP generates awareness activities on falling from height and road traffic accidents are the main causes of SCI (Annual report, 2017). In CRP they get rehabilitation service and after capable of doing work they return to home. CRP helps a SCI patient in his full rehabilitation such as help a patient to perform activities of daily living (ADL) independently and provide them training so they can engage in income generating activities after returning to community.

Occupations can be explained as a contextually bound synthesis of meaningful doing, being, belonging and becoming which influences health and well-being. The components are contributing to well-being such as satisfaction of happiness, personal relationships, social connection, safety and feeling part of a community, all these are influencing to the occupation (Ekelman et al., 2012). And there is general agreement of well-being includes the presence of positive emotions and moods (e.g., contentment, happiness), the absence of negative emotions (e.g., depression, anxiety), satisfaction with life and fulfillment and positive functioning. There are some challenge in the quality and pace of life for the individual, including technology which may imbalances in life roles (AOTA, 2018). If there are role imbalances it is likely to decrease life satisfaction and as well as affect to well-being, Because Guinseit et al., 2018 stated that there are some domains of well-being and role imbalances are one of them. About how we manage and understand about their daily engagements in different occupations and which influences their well-being. A study Marcel et al., 1998 explained that life satisfaction of spinal cord injured persons living in the community is less satisfied with their lives than persons of the normal population group. So, it means they do not lead a healthy life or they are not satisfied according to their less engagement in activities or to get opportunity or having challenges after returning to community. Supportive work environment promotes the person's well-being. Considering the challenges, it is essential to promote the wellbeing of the experienced patient in order to retain them (Zhao et al., 2015). Another study showed that, being and becoming promote well-being and provide further insight into the relationship between occupation, identity, meaning, and well-being (Ekelman et al., 2012). But no sufficient information has been found about the occupational engagement and well-being in Bangladesh. Again, Van Praag et al., 2003 found that, Subjective well-being depends on achievements in various spheres of life such as health, , leisure and work. There is a good combination of health and well-being even health and wellness in the key practice area in 21st century. An individual's health is directly related to the physical as well as emotional well-being (AOTA, 2018). So, the intention of this paper is to explore the understanding about occupational engagement that promotes well-being among SCI patient after rehabilitation.

### 1.3 Significance

When the people with SCI returns to their community, he faces many challenges in his living area as physical, social, mental challenges even they may face many challenges in their workplace. Because they might have low self-esteem, social conduct, support of family, society problem. This type of factors may have negative impact in their life, which decreases their well-being or they may have very good self-esteem or family support which may influences his well-being.

According to definition of well-being, 'it is a broad category of phenomena that encompasses life satisfaction, satisfaction with important life domains, and positive and negative effect also how one takes care of self, and how one balances one's life' (Wilcock, 2006). So, it means after SCI an individual participate in different activities thus it effects on their well-being.

When people become unhealthy, they might feel depressed and hopeless about the future and not want to burden of others with their feelings. It is through understanding this relationship that we can create contexts for enabling individuals,

communities and society to engage in meaningful occupations that promote health and well-being. Moreover we can say the objective of the study will significantly contribute to the person with spinal cord injury to understand about their occupational engagement and well-being. Studies with sufficient information have not been found about occupational engagement and well-being in Bangladesh. So, by this study patient with paraplegia will be benefited for their rehabilitation and help them to lead a healthy life with satisfaction. The researcher will try to fulfill the gap between occupational engagement and well-being and for professional practice.

#### 1.4 Operational Definitions

**Subjective well-being:** Subjective well-being (SWB) refers to a broad category of phenomena that encompasses life satisfaction, satisfaction with important life domains, and positive and negative effect. It includes beliefs about health and wellness, how one takes care of self, and how one balances one's life (Wilcock, 2006).

**Occupation:** Occupations can be defined as activities of daily lives or an activity that a person spends time doing by using a particular place. It is about a person's regular work or profession; any activity on which time is spent by a person (Morris & Cox, 2017).

Occupational Engagement: Occupational engagement can be defined as involving in any purposeful activity with interest, independence and full participation. Engagement is identified as a key theme and described as 'occurring' when the individual is ready and interested in taking part in an activity and the opportunity to do so presents itself (Brown & Kandirikirira, 2007). Using this definition, engagement is seen to be a positive and rewarding concept, with more meaning and value ascribed to it than participation. Occupational engagement is positioned within a framework of personal value and perceived consequences to participation. Occupational engagement is the involvement in an occupation with current positive personal value attached to it (Morris & Cox, 2017). Engaging occupations require more involvement than those occupations that just interest the individual.

#### 2.1 Spinal Cord Injury

Spinal cord injury (SCI) is the injury of the spinal cord from the foramen magnum to the cauda equina which occurs as a result of compulsion, incision or contusion. The spinal cord plays crucial role in various functions of human body including the movement of limbs and the transmission of sensory and motor nerve impulses to and from the brain. The spinal cord is part of the nervous system and facilitates the interactions between the brain and the rest of the body. The spinal cord acts as a bridge, communicating constantly with the brain, receiving and sending information from and to every part of the body (Carlos, 2006). The number of people with SCI living in the United States is currently estimated to be approximately 288,000 persons, with a range from 247,000 to 358,000 persons and about 17,700 new SCI cases each year (NSCISC, 2018). Every year, between 250 000 and 500 000 people suffer a spinal cord injury (SCI) around the world with annual global incidence is 40 to 80 cases per million population (WHO, 2013). Spinal cord injuries are described as either complete or incomplete. In a complete spinal cord injury there is full loss of sensation and muscle function at the distal the level of the injury. In an incomplete injury there is partial preserving of sensory and motor functions below the level of the injury. In most cases both sides of the body are affected equally. It is said that, Up to 90% of SCI cases are due to traumatic causes (WHO, 2013).

#### 2.2 Complications of SCI

The most frequent complication of SCI are the neurogenic bladder and bowel, urinary tract infections, pressure ulcers, orthostatic hypotension, spasticity, heterotrophic ossification, contractures, autonomic dysreflexia, pulmonary and cardiovascular problems, and depressive disorders. These complications are directly related to the patient's life expectancy and quality of life. Negative changes occur in the patient's perception of health due to complications resulting from SCI. Pressure ulcers, spasticity, contractures, bladder and bowel problems especially cause delay of integration with society and psychosocial distress for patients (as cited Hitjig, 2008)

#### 2.3 There are two types of spinal cord injury patient

Tetraplegia: An injury that refers to impairment or loss of motor and /or sensory function in the cervical segments of the spinal cord (Kirshblum et al., 2011). It causes quadriplegia-paralysis of both arms and both legs.

Paraplegia: If the injury to the spinal cord occurs lower in the back it can cause paraplegia-paralysis of both legs only. There may be involvement in the trunk, bowel, bladder and sexual dysfunction (Hasan et al., 2009). This condition has a major negative impact on all areas of the individual's physical and psychosocial functioning (Kirshblum et al., 2011).

#### 2.4 Common causes of SCI in Bangladesh

A study in Bangladesh aimed to investigate life expectancy of people with SCI revealed that, falling from height, either from trees, construction works, electric poles or roofs, was found to be the most common cause (40.30%), falling while carrying a heavy load on the head was second most common cause (16.0%) bull attack and diving into shallow water as traumatic causes. Among the non traumatic cases of SCI, spinal tuberculosis was found to be the most common cause, comprising 7.0% (Hoque et al., 2012).

So, the most common causes of SCI in the world are traffic accidents, gunshot injuries, knife injuries, fall and sports injuries. SCI occurs when there is damage to the spinal cord either from trauma, loss of its normal blood supply, or compression from tumor or infection. SCI causes serious disability among patients.

#### 2.5 Functional Outcomes of SCI

As the study participants are people with SCI who are paraplegic so, the functional outcome among complete paraplegic patient are given below-

Level of injury	Functional Outcome	
T1-6	• Full function of upper limbs and hands means physical	
	independence for personal care and ADLs	
	Able to lift transfer independently	
	May require assistive equipment due to lack of trunk	
	stability	
	• Independent with manual wheelchair • Able to drive	
	with hand controls.	
T7-12	As for T1-T6 with greater preservation of trunk function,	
	improving balance and therefore able to complete more	
	challenging tasks e.g. 180 degree transfers with greater	
	ease	
L1-S5	Independent for personal care and ADLs	
	Able to lift transfer independently with potential to stand	
	transfer	
	• Independent with manual wheelchair with potential to be	
	able to ambulate with the aid of lower limb orthoses and a	
	walking aid	
	Able to drive with hand controls	
	Able to live independently	

On the other hand, Incomplete SCI is an injury involving some preservation of motor and/or sensory function in the lowest sacral segment of the spinal cord, indicating that there is some preservation of motor and/or sensory function below the level of the lesion (West Australia State Spinal Injury Unit, 2013).

#### 2.6 Occupational Experiences of people with SCI

A study found a lower life satisfaction in persons with tetraplegia than in persons with paraplegia (as cited Marcel, 1998). Kielhofner 2008, reported that many individuals with SCI experience discontinuity to involve in different activities after traumatic injury, and lack of such ability to continue even leisure activity becomes a defining aspect of injury experience. Considering the research reports, one's ability to engage frequently in particular activities as leisure activities are very essential because when an injury has occurred, and the person become unable to live a healthy life. Occupational therapists assess the patient's limitations and plan the occupational activities for their self-involvement. Occupational therapist also implement the people with Spinal cord injury depending on social and cultural characteristics of individuals, level of education, personality traits, interests, values, attitudes and behaviors before and after the injury (Youngstrom, 2002). Whether, the people with spinal cord injury (SCI) face major challenges on their occupational role, preferred lifestyle, expression of sexuality and in many other areas (Trombly, 2003).

#### 2.7 Occupation or Occupational activities

According to American Occupational Therapy- AOTA 2014, occupations or occupational activities are the daily activities which people are regularly engaged with. Occupation can be Activities of daily living (ADLs), Instrumental activities of daily living (IADLs), Rest and sleep Education, Work, Play and Leisure (AOTA, 2014). Occupation can also be referred to a central concept within the domain of occupational therapy. Occupation can be a term of what people do and engage in whatever alone or with other in their everyday lives (Wilcock, 2006). It is said that, Doing occupations provides a mechanism for social interaction, societal development, and growth (Wilcock, 2006).

Occupations mainly focus on the term doing, being, becoming and belonging. Doing refers to goal orientated activities. The term being refers to engaging in actual situation. The term becoming comes through doing and being. It influences the occupational identity and occupational identity influences well-being. Belonging refers to develop the social relationship while doing. It is a part of strong desire where they belong which includes meaningfulness of their doing (Ekelman et al.,

2012). People engage in these by the flow of their experiences and these components-doing, being, belonging and becoming strongly associated with occupational engagement.

#### 2.8 Occupational Engagement

According to Adams et al., 2011 study, Occupational engagement is widely regarded as integral to healthy aging. Wilcock (2006) stated that, Occupational engagement encompasses what people actually do, where they do and with whom they spend their time and the perceived level of competence and meaningfulness of their time use for the activity. Wilcock's occupational perspective of health is relevant to health promotion and in its concern with enabling people to increase control over and to improve their health (World Health Organization, 2006).

According to Kielhofner 2008, engagement in the occupation, interaction with the environment is crucial as the environment shapes occupational form, performance and meaning. Occupational engagement depends upon different contexts. For example, geographic, physical, socio-cultural, political, institutional and economic contexts create demands and resources to which people must respond. Such contexts play an important role in occupational engagement (Rowles, 2003). But when a person's capacity in relation to the environmental demands creates barriers for an independent and socially rich life, which can impact negatively on his/her potential to maintain independence (Wahl et al., 2009).

#### 2.9 Categories of Occupation

According to American Occupational Therapy Association (2014) There are about eight categories of occupations such as the first category includes daily activities that aims to taking care of own body as bathing, dressing, eating, feeding, combing, brushing mobility, bowel bladder management etc. the second category includes instrumental activities of daily living (IADL) that support ADL within home and community such as communication, meal preparation, shopping, community mobility, financial management, care of other, health and home maintenance, religious activities and safety maintenance. The third category includes preparation and participation in rest and sleep. The fourth category includes formal and informal educational activities. The fifth category includes work related activities such as

seeking employment, job performance volunteer exploration. The sixth category includes play activity that provides positive effects and enjoyment. The seventh category includes getting motivated and engage in leisure activity. The last category includes social participation which provides organized behavior that is expected in given social system such as social participation in community, with family, peer and friends (AOTA, 2014)

Meaningful occupation refers to engaging the person physically, socially and psychologically. Meaningful occupation provides the basis for social participation (Wilson et al., 2009). The occupation which is situated and embedded within structures and context is critical to any perspective on health. People need to participate in or do occupations to meet his or her basic needs which can promote well-being (Wilcock, 2006).

#### 2.10 Health and Well-being

Health is defined as a state of complete physical, mental and social well-being and a resource for everyday life. An individual or group must be able to identify and realize aspirations, satisfy needs, and change or cope with the environment (WHO, 2006). Health and well-being are understood to be promoted through the ability to make purposeful and meaningful every day choices about what to do (Townsend and Wilcock, 2004). Occupation in which people engage has long been known to influence health and well-being (Creek and Hughes, 2008). Engagement in meaningful occupation, a concept central to occupational science, has been identified, not only as essential to maintain health, but as essential for survival (Wilcock, 2007).

A number of research studies demonstrated that higher levels of quality of life, life satisfaction, and subjective well being are associated with increased levels of quality and social contacts. Subjective well-being and life satisfaction of individuals with spinal cord injury (SCI) tend to relate to community functioning and social interactions, instead of injury levels or levels of functional independence (Clayton & Chubon, 1994).

Diener, 1994 stated that subjective well-being "includes all of the lower-order components such as life satisfaction. Life satisfaction refers to a conscious global

judgment of one's life including the pleasantness and unpleasantness of one's emotional life". Well-being is a general term that encompassing the total universe of human life domains, including physical, mental, and social aspects" (WHO, 2006). These domains explain as-

- Physical Well-Being includes being free from any disease or illness (Wilcock, 2006). It also includes beliefs about health and wellness, how an individual takes care of him/herself, and an individual tries to balance his/her life (Wilcock, 2006).
- Mental Well-Being usually involves thoughtfully choosing the activities that someone wants to do in order to develop oneself as a person (physically, cognitively, and emotionally) (Wilcock, 2006). For example, mental well-being enables an individual to find a meaningful life or search for a meaning of his life, to be reflective, solve problems, develop decision-making skills, clarify beliefs and values, cope with stress, do adjustments and be flexible and adaptive.
- Social Well-Being is refers to achieving a meaningful relationships with family, friends, and people in the community (Wilcock, 2006). It also involves balancing his time with others and time for himself.

#### 2.11 Factors Contributing to Subjective Well-Being

The key Factors of subjective well-being are self-acceptance, positive relationship with other people, autonomy, environmental mastery, purpose in life and personal growth (Diener, 2003). There are some other factors contributing to well-being such as-

Age: Nadler and Boyd (1990), showed that younger people and people who acquired their impairments at an early age, reported higher levels of satisfaction with life. Stensman 1994, reported that quality of life is less well perceived when impairments occur after the age of 35 and tends to increase up until the age of 50 (on average) and then decrease slightly thereafter. It is expected that younger age is associated with higher perceptions of well-being. Older people who have a lack of personal autonomy to make own decisions and to be in control with the system thus causes

lack of opportunity to perform their meaningful occupational activities (Ibrahim & Dahlan, 2015).

Income: Caldwell and Weissinger's (1994) studies found that income was a significant predictor of boredom in leisure. It is expected that higher levels of income associated with higher perceptions of well-being (Ibrahim & Dahlan, 2015). Age and income are the only socio-demographic variables to predict subjective well-being.

Length of injury: Length of injury plays an important role when explaining the leisure experience of people with SCI. People who have just completed rehabilitation and have returned to the community often are overwhelmed by the many challenges faced in the community (Dattilo et al., 1998). People with a longer length of injury might have a better awareness of the resources available for leisure opportunities. It is expected that longer experiences with SCI will be associated with higher perceptions of well-being.

Leisure: Perceived freedom in leisure indicates one's perceptions of control and competence in activity participation; Individuals with higher scores on leisure participation are more likely to experience higher perceptions of well-being (Lee & McCornick, 2004).

Social and community participations: Social participation can be defined as supporting social interdependence, via involvement in intertwining occupations that encourage chosen or desired engagement in activities that facilitate social situations with others such as the community, family, peers and friends (AOTA 2014). Some researchers reported that level of community activity participation is a significant factor in predicting quality of life of individuals with SCI. Occupations that involving health and well-being and leisure participation received strong evidence that demonstrated continued social participation and reduce social isolation (Dickens et al., (2011)

Considering these factors, one's ability to engage frequently in recreation activities, community and social participation in accordance with their age and income are highly associated with their life satisfaction that help them to lead a meaningful life.

#### 2.12 Domains of well-being

Subjective well-being actually describes as how people broadly evaluate their own lives. There are many life domains, and research is reviewed that has related autonomous and controlled motivation to education, parenting, work, health care, sport, and close relationships. The term well-being contains some domains.

A study found that there are five domains of well-being as 1) social connectedness with people and communities includes emotional support, social supports and reduces social isolations 2) Safety of individual 3) stability 4) mastery including negotiating skills, choice, self-esteem, self-confidence and empowerment 5) meaningful access to relevant resources to meet their basic needs and reducing barrier (The fullframe initiative, 2015). Another study mentioned that there are three main domains of well-being such as health, personal relationships and life as a whole. By the study they also found essential domains of well-being as satisfaction with what currently happening, achieving in life, personal relationships, future security and feeling part of a community (Grunseit et al., 2018).

#### 2.13 Occupational engagement (OE) and well-being:

Several studies have shown many concepts of occupational engagement and well-being. Such as, positive OE between person and environment influences overall well-being among person with SCI (Ludwig, 2004). On the other hand, meaningful occupations such as doing, being, belonging, to be a part of something beyond self, achievement and ability to balance the life domains promote individual's well-being (Ekelman et al., 2012).

#### 3.1 Research Question

What about daily occupational engagement and well-being among person with spinal cord injury (SCI) after rehabilitation?

#### **3.2.1 Study Aim**

The general aim of the study is to understand about occupational engagement and subjective well-being among person with spinal cord injury after rehabilitation.

### 3.2.2 Specific Objectives

- a) To explore participants understanding about occupational engagement after SCI.
- b) To explore the understandings about well-being after SCI.
- c) To understand the importance of occupational engagement among persons with SCI after rehabilitation.
- d) To explore the challenges of person with SCI to involve in occupation after completion of Rehabilitation according to their opinion.

### 3.3 Conceptual Framework

While engaging in different occupations having the followings negatively/positively-

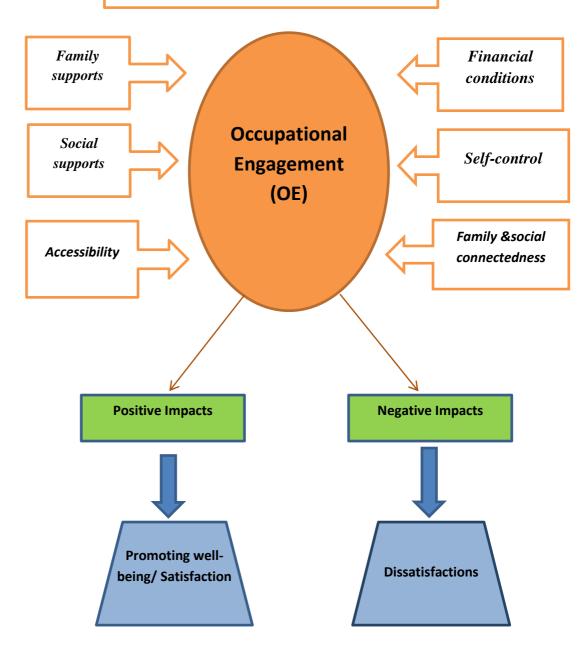


Figure 1: Conceptual Framework of the Study

#### 3.4 Study Design

Qualitative research methodology was used for this study, because it is helpful to find out the perceptions of people in particular settings and to understand their perspective. The researcher used this method to fulfill the aim and objectives of the study. Qualitative research is exploratory in nature by which the researcher can gain insights into another person's view's, opinion, feeling and beliefs within their own natural setting regarding the person of SCI (Ohman, 2005). Qualitative research helps to explore depth information and also helps to identify client's thoughts, ideas, feelings, attitudes and perceptions (Hissong et al., 2014).

Phenomenological study design is best suited method to complete the study in the given period. In the qualitative study, Phenomenological study design is incorporated with a focus on understanding the experience to phenomenon of the situation of participant's occupational engagement after returning back to their home or living community. This research design is used to know about the living experience of the participants (Waters, 2017). The aim of the research is to explore the understanding of occupational engagement and well-being from SCI patient from their community and this study design helps to explore the participant's views, perceptions and experiences about their well-being while engaging in different activities. So, Phenomenological study design will help the researcher to collect information from participants own experience by visiting to their community and to collect data accurately.

#### 3.5 Study Population

The study was conducted from People who diagnosed with Spinal Cord Injury (SCI) and who have returned to the community after their discharge from rehabilitation center/service. The admitted patient with spinal cord injury who has returned back to home and at least 1 year of experience living in community.

#### 3.6 Study Setting

Participant's living place in the community and working area.

#### 3.7 Study Period

The period of the study was from August 2017 to April 2018 however the researcher got time to collect data from 1<sup>st</sup> January to April 2018.

#### 3.8 Study participants

The number of participant of the study was 13. The main participant cohort was about 50 people who match the inclusion criteria. But the data was saturated during the 13 participant by means of giving same result so the researcher had to stop with 13 participants.

#### 3.9.1 Inclusion Criteria

- Adult People with SCI (18-60 years)
- People with SCI who has at least 1 year of experiences with SCI or completed their rehabilitation.
- People with SCI who are wheelchair dependent.
- People with paraplegia.

#### 3.9.2 Exclusion Criteria

- People with SCI below age 18
- People with SCI Tetraplegia
- Past neurological deficits (dementia, head injury)
- Person with mental disorder and communication deficits.

#### 3.10 Participant selection process

The researcher has selected convenient sampling procedure to select the participant for the study. In this sampling method, participant is taken from a group of people easy to contact or to reach or which is convenient. It helps data collection in short duration of time (Saunders et al., 2012). This sampling method involves getting participants wherever researcher can find them and typically wherever is convenient. In convenience sampling no inclusion criteria identified prior to the selection of subjects but all subjects are invited to participate in the study (Bailey, 1997).

#### 3.11: Data Collection Instruments/Tools

- a) Information Sheet and Consent Form: It is the formal statement or agreement between the researcher and the participant before conducting the interview. An information sheet refers to the details information about the researcher aim objectives of the study, study duration, institution affiliation, and identity of investigator, participant's confidentiality, participant's rights, benefits and ethical issues. Researcher has taken permission in the consent form by signature or finger print from each participant before conducting the interview. At the beginning the researcher informed the participant that their participation in this study is voluntary also the researcher has ensured the participant about research topic and ethical approval that this interview will not be harmful for them and their identity will be kept confidential. The researcher also explained how their information will be useful to the study and the time duration. The researcher also added that they have full rights to decline answering any questions or refuse to participate any time. In the consent form the researcher then took signature and then started the interview. The consent form was given to the each participant to read it out or researcher read it verbally so that the participant listen it during conducting the face to face interview. This consent form and audio tape transcript only accessible to the supervisor and researcher. According to Depoy & Gitin 1998, audio taping is fundamental strategy in qualitative research.
- b) The semi structured questionnaire, which was developed by the guidance of personal well-being index PWI, 2013. The semi structured questionnaire is made up with the relevance of participant's subjective well-being and occupational engagement. It is based on thinking about their own life and personal circumstances. This questionnaire aimed to find out in depth information from the participants about the pattern of occupational engagement as well as finding out the barriers of the community from their perspective.
- c) Patient survey list of Spinal cord injury paraplegic patient
- d) Mp3 recorder

#### 3.12 Data collection method

Researcher was conducted face to face interview with a semi structured question for data collection. With semi structured question, participants got more freedom to explain their opinions and that researcher could go out from the boundary of fixed question to understand their experience by asking related questionnaire. The researcher had conducted face to face interview by building up rapport with the participant first. Face to face interview helps the researcher to determine participants understanding of the questions by observing their facial expressions. Before conducting the interview the researcher ensured the participant about the aim and objective of the study and also made him aware about the consent form of the research and took the written signature or finger print with their agreement. Before starting interview, researcher also alerted the participant about the conversation which will be recorded by the mobile recorder. Researcher asked some open ended questions to the participant relevant to their answers to reach more depth of their understanding. The researcher also took some observation notes for each participant by visiting to their living community about how they work, lives, communicates and their expressions during communications.

#### Field test

Before staring the data collection, researcher conducted field test with two participants. The test had been performed to determine the difficulties existing in the questionnaires as well as the procedure of data collection. By this test, the researcher remodeled the questionnaire such as two of the questions were modified which was similar and 2 additional questions had been added to the main analysis of questionnaire so that they could understand easily and provide the information clearly related to the study. During the interview, researcher informed the participant about the aim and objective of the study also took written permission by consent form.

#### 3.13 Data management & analysis

Researcher has used Qualitative thematic analysis to analyze the data of understanding about occupational engagement and well-being among SCI patient. In this type of analysis, coding and pattern of themes are derived from text data (Braun & Clarke, 2006).

At the first stage of data analysis the researcher transcribe the interview Bangla to English from MP3 recorder. The researcher listened to recordings several times to recognize what the participant wants to say in the interview. After the transcription of each data researcher again listened the recording to ensure the validity of data. Then the researcher organized the data according to each interview question related to objective. Reading and re-reading the data, researcher find out initial codes and then generated themes collating the codes under each objective.

#### 3.14 Quality control and quality assurance

The semi-structured questionnaire that is prepared by the researcher to conduct the interview, were pre-tested. Questionnaire was translated into Bengali for better communication with the participants. After each interview questionnaire were checked for possible error. 2 field surveys had been conducted by the researcher before going to the final data collection of the study.

#### 3.15 Ethical considerations

The researcher granted approval from the research supervisor and head of the department of Occupational therapy, BHPI an academic institute of Centre for the Rehabilitation of the Paralysed (CRP) to conduct the study. Then permission was taken from the CBR department of CRP for data collection of the participant from the patient list. The investigator took consent from to the participants who were interested to participate in the study and informed verbally about topic and purpose of study. The researcher ensures that the SCI department and community people will not hamper by this study. It is ensured that the participants will not deprive from any therapy session by this study. During home visit, the researcher took permission from

CBR department and In-charge of SCI to access in the community participant for collecting data. The researcher has promised the participants that all information will be kept confidential and would not expose their identity or address except research supervisor. Recorded data, written data, transcript will be destroyed after six months following the study. Participants were also informed that they would not be harmed due to being a participant of the study.

### **CHAPTER 4: RESULT & DISCUSSION**

Result and discussion are described in same chapter because this is common practice in reporting on qualitative studies (Stephenson & Wiles 2000). Result has been analyzed by the data which is collected from the participant's understanding and practical experiences. Whereas discussion is presented to make the study more clear (Hissong et al., 2014). These understandings and experiences are regarding to their understanding of well-being. The objectives of the studies were to explore the understanding about occupational engagement, to explore about well-being, importance of occupational engagement and the challenges that influencing occupational engagement as well-being. Collating the codes the researcher has generated four potential themes to express the overall story of the data. The study has resulted five major themes. These are as following:

Theme 1: Engagement in routine based household and productive work is referred to occupational engagement.

Theme 2: Satisfaction in OE is influenced by physical & social environmental factors.

Theme 3: Psychological, social, family and financial capabilities are the prioritized enablers to optimize well-being in daily engagement.

Theme 4: Engaging in occupation ensures mindfulness and pleasure in living.

Theme 5: Lack of accessibility, safety, poor social and family relationships have influences in well-being.

Now these themes are discussed below-

Theme 1: *Engagement in routine based household and productive work is referred* to occupational engagement. The analysis of the research has resulted a general description of 13 participants with spinal cord injury and provided a background of understanding their occupational engagement. They described what they think about what is occupation to them from their perspective. This theme means that if an individual doing any routine based activities whatever it is household work or productive work are occupational engagements.

One participant said that, 'Occupational engagement is activities of daily routine. such as brushing, taking breakfast, taking shower, taking meal, gossiping with friends, watching TV, listening songs and then dinner'. Here, in his daily routine he mentioned, the activities that starts from early in the morning to night going for sleeping (Table 1). That means, he included his self-care and leisure in his occupational engagement. On the other hand, Engaging occupations have been found to be analogous to work in terms of the seriousness and commitment with which they are pursued (Jonsson, 2008).

Other participants added that, 'Managing and running the shop, doing flexiload or involving to any income generating activities (Table 1) are occupations and being engaged to it, is occupational engagement'. This means those participants want to include their productive works as occupation. They think productive work is meaningful and promote well-being. A study explains when an individual is less productive or not capable of engaging in occupation or performing ADL he loses hopes and ultimately they have less satisfaction with their life (Lee & McCormick, 2004). Solberg et al., 2002 presented that individuals who have more reasonable income desires are more satisfied than those whose desires cannot be fulfilled by their incomes.

Another participant said that, 'My own satisfaction during work is occupational engagement'. This means performing all the activities has to be satisfied by him. So, one individual should have satisfactory performance to their occupations while engaging in it. A study claims that, occupational engagement that refers to more involvement in different occupations with the interest of the individual (Morris, 2017).

Some participant mentioned that, 'being connected to activity which is most important and meaningful is occupational engagement'. From their perspective, which activities are necessary and meaningful for their lives, are occupation to them.

Table 1

Aim	Objective		Coding	Themes
То	1. To explore		Maintaining daily routine but not necessary to be	Theme 1: Engagement
understand	their		structured	in routine based
about	understanding	0	Always connected to a work	household and
occupational	about	ntr	Performing meaningful activity	productive work is
engagement	occupational	ÇO	It is not occupation if it has no importance	referred to
and	engagement	Self-control	Make sense of human-being	occupational
subjective		S	Provides own satisfaction during work	engagement.
well-being			Self-care, Participating in social program and	
among			financial earning	
person with			To do what is liked and to avoid what don't like	
spinal cord injury after			Very few people are Highly satisfied about	Theme 2: Satisfaction
rehabilitation			occupational engagement	in OE is influenced by
Tenaomitation			Most of moderately satisfied	physical & social
·			Engagement in productive work (Managing	environmental factors.
		Financial productiv work)	and running the shop)	
			Productive work (Doing flexi-load)	
		Financial (productive work)	Indoor works and outdoor works by means of	
			income	
			Unemployment results as depression	

Many of them also included social bonding to their occupational engagement about how they like to lead their lives. So, overall according to their understanding, occupational engagement is meaningful involvement in self-care, productivity and leisure that influences own satisfaction.

Theme 2: Satisfaction in OE is influenced by physical & social environmental factors. It is seen that many of the patients are describing their occupational engagement based on their surrounding environment (Table 1). If the environment is suitable for them then he is well but if the environment is not accessible to him then he can't be engaged to any occupation thus bring dissatisfaction in life. The physical environment constitutes both a barrier and an enabler when an individual performing daily occupation (CAOT, 2002). One participant mentioned that, 'I cannot do all of my work due to physical barrier'. However increased level of complexity of daily occupations decrease self-rate health and well-being (Erlandsson, 2011).

Theme 3: Psychological, social, family and financial capabilities are the prioritized enablers to optimize well-being in daily engagement. This theme means participating in daily activities, there are some influencing domains that is strongly associated with their well-being. Many of the participants have explained as followings (Table 2):

One participant explained that, 'when personal relationship with family and society are good with me, which bring well-being as well as satisfaction of my life. Moreover, family support while doing an activity and good participation in society promotes their well-being. One participant added that, when i do not get enough supports from family members and society i feel sad and remain deprived from everything. Similarly, social connections and encouragement from others strongly endorsed by participants can influence health and well-being (Garci & Mandich, 2005).

Other participants added that, involvement in shop keeping as well as income source is responsible issue for being well. So, they give more priority to their productive work as they need to maintain their family expenses. If they can manage themselves and their family being earning member that provides satisfaction of their lives. Some also included about being independent in their live. They also added that, 'if there is no income then no live'. It is like being caged to home and living a meaningless life.

Table 2

Aim	Objective		Coding	Themes
	2. To explore		Feels good when involved to any activity and create cheerful	Theme 3:
	their		mind	Psychological,
	understanding	0	Occupational engagement makes feel as 100% well.	social, family and
	about well	ntr	Belief on Allah for better life	financial
	being	-00	Mental commitment to work	capabilities are
		Self-control	happy to engage in daily activities	the prioritized
		S	Ability to adjust with present situation	enablers to
			Physical illness creates bad impression to work.	optimize well- being in daily
			Strength is required to engage in work	engagement.
		cial	Earning money to be independent	11181181111111
		Financial	Poor Financial situation due to injury	
			Co-operating with others like gossiping with friends are	
			favourite occupation	
		_	Good relationship with society create feeling of wellness	
		cia	no help from society	
		SO	Lack of Family support creates depression.	
		pue	Sometimes it is impossible to run a shop alone	
		Family and social	Others are supportive and caring after the accident	
		ımı	Disconnected with family member	
		Fē	Loneliness because nobody to help	
			Family supporting now because they got support before	
			Injury	

Some participant talked about their loneliness and lack of security. They meant it is very hard and quite impossible to live alone without and family member so how they will be well in this situation. There is nobody to help them or look after them. Some participant has lack of safety and leads a risky life. On the other side some are living with enough security and living a healthy live. One participant added that, 'as I have no family support so I do not engage to any work'. Some factors as engagement, negative affect to health problems, finances, career Opportunities, living circumstances, and interpersonal relationship during engagement that affects subjective well-being (Krause, 1998).

Some participant has focused on their spiritual life and keeping belief on their religious they are happy. Bonding to spiritual issue is the most influencing domain for their well-being and they said, they are happy how they are living like now. Spirituality is the aspect of humanity that refers to the way individuals seek and express the meaning and purpose of their life and the way they experience their connectedness to the moment, to self, to others, and to nature (Puchalski et al., 2009)

Meaningful, well-organized, supported and efficient occupations are associated with higher levels of well-being (Anaby et al., 2010). So, in this theme the participant understand their well-being if these domains (Psychological, social, family and financial) have positive effect on their life as they understand their well-being. But they are not satisfied if their income source, self-esteem, family support, security and social relationships are poor.

# Theme 4: *Engaging in occupation ensures mindfulness and pleasure in living*. According to the theme 1, as they provide most important to their daily activities and getting involved to that is called occupational engagement. So, it means occupational engagement is highly essential for them. (Table 3)

Some participant said that, 'it feels good getting engaged to an activity and feels bad when not being engaged to work'. So, OE is also effective for their feelings. One participant also added that it feels weak from mind or mental well-being unless any activity. They believe it is compulsory to earn for living. Occupations that promote utilization of creativity are meaningful because they empower humans to relate to themselves, each other and the world around them (Pollard, 2011).

Table 3

Aim	Objective		Coding	Themes
	3.		Mind gets fresh by participating own work	Theme 4: Engaging in
	Importance	_	Passes quality time by getting engaged to	occupation ensures
	of	<u> </u>	different occupations	mindfulness and
	Occupational	ntr ogi	Highly important to recite Holy Quran, and feels good	pleasure in living.
	engagement.	양물	(spiritual)	
		Self-control (psychological)	Occupations keep one-self well	
		o, g	Without any activity it feels weak in mental health	
			Satisfied with present achievement	
			Modify the work and manage to adjust anyhow	
			Love to listen music and playing game (Leisure)	
			To fulfill desires of living and gives hopes	
		Financial	Feels good to participate and feels bad when cannot	
			participate	
			Who seat alone ideally nobody accept him in society	
		⊗ ⊡	Customer leaves if they are offered to help in shop	
		<u>8</u>	Sewing cloths that makes feel better	
		Social	Involving in occupation to survive	
		S	Engaging in occupation to earn	
			It is compulsory to earn for living	

Mindfulness support work engagement in a direct way. It is about fulfilling the states of mind that are associated with higher engagement in the specific occupation. Work engagement influences mindfulness and well-being (Malinowski & Lim, 2015). Another participant expressed that, 'occupational engagement is mandatory to meet basic needs'. It means through engaging in such occupations they fulfill their basic need for living as well as to fulfill want of living. It is obvious to survive. They also added, occupational engagement brings hope to them for surviving independently. So, engaging in different occupations they can fulfill their basic needs which give them pleasure and keep them mindful (Malinowski & Lim, 2015).

# Theme 5: Lack of accessibility, safety and poor social, family relationships have influences in well-being (Table 4).

This means there are some challenges in engaging to their occupations. Such as accessibility to move through wheelchair, lack of transport for them, family members are not supporting to them, society people doesn't help them to collaborate or to participate in programs, they lead an insecure life and lastly suffer loneliness as they think they are neglected from society that produces negative effects on their well-being.

As a study said, the person with SCI can have a positive impact on well-being if the bio-psychosocial dysfunctions were reduced and activities in everyday life were improved. Engaging for long-term period different daily life areas can improve physical and functional state, functional skills and abilities, maintaining physical activity (Sidlauskiene, 2017).

But one participant said that, 'As I don't involve in social work, so I don't get respect from them'. So engaging in social work and involvement with society people is crucial for living a respectful life. And one participant added that, engaging in occupation that is bringing well-being to me. So, being engaged in work that means being well to her. It is said that, lack of engagement in occupational activities and lack of meaningful social relationship can contribute to the lack of purpose in life (Hedberg et al., 2010). An absence of meaningful occupation and social participation may hinder to social isolation (Dickens et al., 2011).

Some participant added that, Transports are not accessible to them. One also included, 'I can't reach to my favorite place due to lack of accessibility'. She mentioned that, I have a favorite park beside my house. Now I can't go there by wheelchair because the park doesn't allow wheelchair users in there. So, it makes her sad due to his disability. On this point of view, the participant doesn't blame her disability but to people's mentality. So, if one can recover the challenges or accept it, he is satisfied in his life.

Table 4

Aim	Objective		Coding	Themes
	4.	>	Nobody to help to overcome the obstacles during propelling w/c	Theme 5: Lack
	Challenges	<u>ii</u>	Unable to reach 1 <sup>st</sup> and 2 <sup>nd</sup> floor	of accessibility,
	hampering	Accessibility	Inappropriate accessibility for w/c user	safety, poor
	well-being		Living alone is very hard like being caged in the house	social and family relationships
		⋖	Difficulty to reach favorite place due to lack of accessibility	have influences
			People judge before giving an opportunity	in well-being.
		₹	Some people stare like disable people are from another world	J
		safety	Less satisfaction with safety during probability of fall	
		Social & s	Less collaboration with society	
			No involvement in social work, no respect	
		000	Continuous sitting ideally more vulnerable for health	
			Poor personal relation with family	
		lo (nc	engaging in occupations are bringing well-being	
		ti ji	Occupational engagement improving health and well-being	
		-cc isfa	Getting engaged to work is being well	
		Self-control (satisfaction)	Doing everything and feeling good	
		J , w	Continuous work makes feel good	

So, the element of challenge supports active engagement by providing growth opportunities and the satisfaction of acquiring new knowledge, as well as the rewarding quality of external attention and feedback when one meets the challenge successfully that brings well-being (Tonneijck, Kine banian & Josephsson, 2008).

### 5.1: Limitation

Limitation is a matter that occurs during conducting the study. Every study has some limitations and those limitations are not in researcher control. This limitation might help during conducting further research related to the study.

- ❖ In this research only people with SCI who are paraplegic, were included. So it is not possible to find out the well-being of tetraplegia patient in community.
- ❖ From the researcher's observation some participant did not express truly their well-being according to their engagement in occupation.
- ♦ Researcher could not access enough participant living their community
- ♦ Participant rated their satisfaction which didn't match to their facial expression.

As limited study has been conducted in Bangladesh relevant to the topic so there were limited resources, books, and annual reports and there was limited journal access. If the researcher would get sufficient information with enough time then the study could be more structured and valuable. But the researcher tried best to seek information conducting the study from the undergraduate level.

### 5.2: Conclusion

The study has been conducted to explore the understanding of occupational engagement and well-being among person with Spinal Cord Injury. From the result of the study, it provides a clear idea of participant understanding about occupational engagement which can be predicted by their physical and social environmental conditions that leads to their satisfaction in life and SWB which is prerequisite for the successful functioning in everyday live. There are also some psychological, social, family and financial issues which enable their well-being in accordance with daily engagement. From participant point of view, involvement in indoor and outdoor work that is necessary for living is occupational engagement. They think Occupational engagement is highly essential for living. On the other hand, if there is

lack of accessibility, safety, social and family supports that provides negative impact on their well-being.

So, the findings will help not only the people with Spinal Cord Injury to be involved in meaningful occupation in his daily living but also they will more conscious about their participation in different activities after their rehabilitation. This study will also be helpful for health professionals who will conduct the relevant study in future.

### **5.3: Recommendation**

After conducting the study, researcher would like to provide some recommendation for the participants of the research.

- ❖ In further research of the area, the researcher should maintain the data collection place and increase the participant and ensure more in-depth interview.
- ❖ In future research, not only the people with paraplegia but also people with tetraplegia should be included which might be more resourceful study.
- ♦ Health professionals should encourage participation and engagement in occupational activities to facilitate the purpose in life.

### Appendix A

### Permission letter for Ethical Approval

November 16, 2017 The Chairman Institutional Review Board (IRB) Bangladesh Health Professions Institute (BHPI) CRP-Savar, Dhaka-1343, Bangladesh

Subject: Application for review and ethical approval.

Dear Sir.

With due respect, I would like to draw your kind attention that I am a student of B.Sc. in Occupational Therapy course at Bangladesh Health Professions Institute (BHPI)- an academic institute of CRP under Faculty of Medicine of University of Dhaka (DU). This is 4-years full-time course and 1- year internship. I have to conduct a thesis entitled, "Understanding about Daily Occupational Engagement and Well-being among Person with Spinal Cord Injury (SCI) after Rehabilitation" under honorable supervisor Md. Mohsiur Rahman, Lecturer of Occupational Therapy, BHPI, CRP.

The purpose of the study is to explore meaningful engagement in daily occupations connected with health and well-being after Spinal Cord Injury who are paraplegic and living in a community. Self-developed Questionnaire will be used to conduct the research. That will take about 30 to 40 minutes to each participant. Related information will be collected from those patients who have been discharged from the CRP. Data collector will receive informed consents from all participants. Collected data will be kept confidential.

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

Sincerely yours,
Nusrat Elahi
Session: 2013-2014
Student ID: 122130110
4th Year student of B.Sc. in Occupational Therapy
BHPI, CRP, Savar, Dhaka-1343.

Recommendation from the thesis supervisor:

Md. Mohsiur Rahman Lecturer of Occupational Therapy Department of Occupational Therapy Bangladesh Health Professions Institute CRP, Chapain, Savar, Dhaka – 1343

### Appendix B

### Approval letter of Institutional Review Board (IRB)



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

(The Academic Institute of CRP)

Ref.

CRP-BHPI/IRB/11/17/160

То Nusrat Elahi B.Sc. in Occupational Therapy Session: 2013-2014, Student ID: 122130110 BHPI, CRP, Savar, Dhaka-1343, Bangladesh

Subject: Approval of the thesis proposal "Understanding about Daily Occupational Engagement and Well-being among Person with Spinal Cord Injury (SCI) after Rehabilitation" by ethics committee.

Dear Nusrat Elahi.

Congratulations.

The Institutional Review Board (IRB) of BHPI has reviewed and discussed your application on 02/10/2017 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 and Bengali version)
3	Information sheet & consent form.

Since the study will be conducted to explore community dwelling spinal cord injury patients' meaningful engagement in daily occupations connected with health and well-being. A Questionnaire will be used to conduct the research which will take about 30 to 40 minutes for each participant. The members of the Ethics committee have approved the study to be conducted in the presented form at the meeting held at 9:00 AM on October 08, 2017 at BHPI.

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

Best regards,

Lellalhanaen

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

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

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

### Appendix C

### Permission letter for Conducting the Study

16<sup>th</sup> November 2017
The Head of the Department,
Department of Occupational Therapy
Bangladesh Health Professions Institute (BHPI)
CRP-Chapain, Savar, Dhaka-1343.
Through: Dissertation Supervisor

Subject: Prayer for seeking permission to conduct the research project

Dear Sir,

With due respect, I am a student of 4<sup>th</sup> year B. Sc in Occupational Therapy of Bangladesh Health Professions Institute (BHPI), the academic institute of Centre for the Rehabilitation of the Paralysed (CRP).. I am seeking permission to conduct the research project as a part of my 4<sup>th</sup> year course module. My research title is "Understanding about Daily Occupational Engagement and Well-being among Person with Spinal Cord Injury (SCI) after Rehabilitation". And I will try to know about participants understanding about occupational engagement and well-being after Spinal Cord Injury (SCI) and the challenges of person with SCI according to their opinion after completion the rehabilitation. And I also can make sure that the study will not be cause of any harm to the participant. For this purpose, I need permission from you to continue my research project.

So, I therefore pray and hope that you would be kind enough you give me the permission to continue the research project for my study.

Sincerely yours,

Musical Elable...

Nusrat Elable...

Nusrat Elabli

4<sup>th</sup> year B. Sc in Occupational Therapy

BHPI, CRP-Chapain, Savar, Dhaka- 1343, Bangladesh.

Approved by:	Signature:
Supervisor Md. Mohsiur Rahman Lecturer, Occupational Therapy Department of Occupational Therapy BHPI, CRP-Chapain, Savar, Dhaka-1343	we may allow her to conduct this Mudy according to proposed methodology.
Head of the Department Sk. Moniruzzaman Department of Occupational Therapy BHPI, CRP-Chapain, Savar, Dhaka-1343	Su. mon

### Appendix D

### Permission letter for data collection



# বাংলাদেশ হেল্থ প্রফেশন্স ইনষ্টিটিউট (বিএইচপিআই)

BANGLADESH HEALTH PROFESSIONS INSTITUTE (BHPI)

(The Academic Institute of CRP)

CRP-Chapain, Savar, Dhaka, Tel: 7745464-5, 7741404, Fax: 7745069

BHPI-Mirpur Campus, Plot-A/5, Block-A, Section-14, Mirpur, Dhaka-1206. Tel: 8020178,8053662-3, Fax: 8053661

তারিখ ঃ ০৭.০১.২০১৮

Forwarded to cialwellore

প্রতি ম্যানেজার রিহ্যাবিলিটেশন উইং সিআরপি, সাভার, ঢাকা।

বিষয় ঃ রিসার্চ প্রজেষ্ট (dissertation) প্রসঙ্গে।

জনাব,

বিএইচপিআই'র ৪র্থ বর্ষ বিএসসি ইন অকুপেশনাল থেরাপি কোর্সের ছাত্রী নুসরাত ইলাহীকে তার রিসার্চ সংক্রান্ত কাজের জন্য আগামী ০৮.০১.২০১৮ তারিখ থেকে ২৮.০২.২০১৮ তারিখ পর্যন্ত সময়ে আপনার নিকট প্রেরন করা হলো।

তাই তাকে সার্বিক সহযোগীতা প্রদানের জন্য অনুরোধ করছি।

ধন্যবাদান্তে

০7/০1/2018 শেখ মনিরুজ্জামান

Su. mes

সহকারী অধ্যাপক ও বিভাগীয় প্রধান অকুপেশনাল থেরাপি বিভাগ

বিএইচপিআই।

### Appendix E

### **Information Sheet**

Nusrat Elahi, a student of 4<sup>th</sup> year B.Sc. in Occupational Therapy in Bangladesh Health Professions Institute (BHPI), the academic institute of Centre for the Rehabilitation of the Paralysed (CRP). As a part of her academic activities, she has to conduct a research project in this academic year. The title of the study is about "Understanding about Occupational Engagement and Subjective Well-being among Person with Spinal Cord Injury (SCI) after Rehabilitation" The purpose of the study is to explore meaningful engagement in daily occupations connected with well-being among person with Spinal Cord Injury after completion of rehabilitation in Bangladesh. Researcher would like to invite you to participate in this study.

Your participation will be voluntary in the study. You can withdraw your participation in anytime. Participants will not get any kind of financial benefit from this study. The study will never be harmful to you but it will help the service user to know about your experience.

All records/data/interview will be kept confidential. The gathered information from you will not be disclosed anywhere except the researcher and supervisor. The study will never publish the name of participant anywhere.

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

Nusrat Elahi Student of 4<sup>th</sup> year B.Sc. in Occupational Therapy Department of Occupational Therapy Bangladesh Health Professions Institute (BHPI), Centre for the Rehabilitation of the Paralysed (CRP),

### Appendix F

#### তথ্য পত্ৰ

নসরাত এলাহী, পক্ষাঘাতগন্দরে পনবাসন কেন্দ (সি আর পি) এর অধিনস্থবাংলাদেশ হেলথ পফেশস্ ইনস্টিটিউটের অকপেশনাল থেরাপি বিভাগ এর ৪র্থ বমের্র ছাত্রী। প্রাতিষ্ঠানিক কার্যের অংশ হিসেবে চলন্ত শিক্ষাবর্ষে তাকে একটি গবেষনামূলক কাজ করতে হবে। গবেষনাটির শিরোনাম "স্পাইনাল কর্ড রোগীদের পুনর্বাসনের পর দৈনন্দিন কাজে সংযুক্তি এবং এর ফলে তাদের সুস্থতার ধরন" এই গবেষণার উদ্দেশ্য হল- স্পাইনাল কর্ড রোগীদের দৈনন্দিন কাজের সংযুক্তি এবং এর ফলে তাদের সুস্থ থাকার ধরন সম্পর্কে জানা। গবেষণাকারী আপনাকে এই গবেষণায় অংশগ্রহণের জন্য আমন্ত্রণ জানাচিছ।

গবেষনায় আপনার অংশগ্রহন সম্পূর্ণ রুপে স্বেচ্ছায়। আপনি যেকোন সময় গবেষনা থেকে আপনার অংশগ্রহন প্রত্যাহার করতে পারবেন। এই গবেষণায় অংশগ্রহনে গবেষক আপনাকে কোন ভাবে আর্থিক সাহায্য প্রদান করবেন না। এই অংশগ্রহন কখনোই আপনার জন্য ক্ষতির কারণ হয়ে দাঁড়াবে না কিন্তু এই গবেষনার মাধ্যমে সেবা প্রদানকারী সদস্যগণ আপনার অভিজ্ঞতার কথা জানতে পারবেন এবং প্রাপ্ত তথ্য সমূহ সেবার মান উন্নয়নে সাহায্য করবে।

আপনার কাছ থেকে/প্রাপ্ত তথ্য সমূহের সর্বোচ্চ গোপনীয়তা রক্ষা করা হবে। গবেষক এবং গবেষণার সমন্বয়কারী ব্যতীত এই তথ্য গুলো অন্য কোথাও প্রকাশিত হবে না এবং গবেষণার কোথাও অংশগ্রহনকারীর নাম প্রকাশ হবে না। গবেষণা সম্পর্কিত যেকোন ধরনের প্রশ্নের জন্য নিম্নলিখিত ব্যক্তির সাথে যোগাযোগ করার জন্য অনুরোধ করা যাচেছ।

নুসরাত এলাহী
বি এস সি ইন অকুপেশনাল থেরাপি (৪র্থ বর্ষ)
অকুপেশনাল থেরাপি বিভাগ
বাংলাদেশ হেলথ প্রফেশঙ্গ ইনস্টিটিউট
পক্ষাঘাতগ্রন্তদের পূনর্বাসন কেন্দ্র (সি আর পি)
চাপাইন, সাভার, ঢাকা-১৩৪৩

### **Appendix G**

### **Consent Form**

This research is part of Occupational Therapy course and the name of the researcher is Nusrat Elahi. She is a student of 4<sup>th</sup> year B.Sc. in Occupational Therapy in Bangladesh Health Professions Institute (BHPI), the academic institute of Centre for the Rehabilitation of the Paralysed (CRP). The study was entitled as "Understanding about Occupational Engagement and Subjective Well-being among Person with Spinal Cord Injury (SCI) after Rehabilitation" The study will be conducted by Nusrat Elahi at the real workplace and living place in the community of the participants.

The aim of the study is to explore meaningful engagement in daily occupations connected with well-being among person with Spinal Cord Injury after completion of rehabilitation in Bangladesh.

I am also informed that, all the information collected from the interview will be only used for study purpose and would be kept safety and confidentiality will be maintained. My name and address will not be published anywhere. Only the researcher and supervisor will be eligible to access in the information for his publication of the research result. I have been informed about the above-mentioned information and I am willing to participate in the study with giving consent.

Signature/Finger print of the Participant:	Date:
Signature of the Researcher:	Date:
Signature/Finger print of the witness:	Date:

### Appendix H

সম্মতিপত্ৰ			
এই গবেষনাটি অকুপেশনাল থেরাপির কোর্সেও একটি অংশ এবং গবেষণাব	গরীর নাম নুসরাত এলাহী। সে পক্ষাঘাত		
পূনর্বাসন কেন্দ্র (সি আর পি) এর অধিনস্থ বাংলাদেশ হেলথ্প্রফেশস্ ইনস্টি	টিউটের অকুপেশনাল থেরাপি বিভাগ এর		
৪র্থ বষের ছাত্রী । এই গবেষনাটির শিরোনাম স্পাইনাল কর্ড রোগীদের পূনর্বাস	নের পর দৈনন্দিন কাজে সংযুক্তি এবং এর		
ফলে তাদের সুস্থতার ধরন। এই গবেষণাটি অংশ গ্রহণ কারী ব্যক্তিদের প্রকৃত	কর্মস্থল ও নিজ আবাস্থলে নেওয়া হবে।		
এই গবেষণার উদ্দেশ্য হল-স্পাইনাল কর্ড রোগীদের দৈনন্দিন কাজে সংযুত্তি	চ এবং এর ফলে তাদের সুস্থ থাকার ধরন		
সম্পর্কে জানা।			
এই গবেষনাতে আমিএকজন অংশ গ্রহ	নকারী এবং পরিষ্কার ভাবে এই গবেষনার		
উদ্দেশ্য সম্পর্কে অবগত।  আমার যেকোন সময়ে এই গবেষনা থেকে নিজেবে	ক প্রত্যাহার করার অধিকার আছে। এজন্য		
আমি প্রশ্নের উত্তর প্রদান করার জন্য করো কাছে দায়বদ্ধ না। এই গবেষণাটির সাথে আমার কোন সম্পৃক্ততা নেই।			
এই গবেষনাটি বর্তমানে এবং ভবিষ্যতে আমার চিকিৎসা ক্ষেত্রে কোন রকম প্র	ভাব ফেলবে না।		
আমি আরও অবগত আছি যে, এই কথোপকথন থেকে নেওয়া সমস্ত তথ্যাব	লি নিরাপদে এবং গোপনীয়তার সাথে শুধূ		
মাত্র গবেষনার কাজেই ব্যবহার করা হবে । আমার নাম এবং ঠিকানা কোথা	ও প্রকাশ হবে না। শুধুমাত্র গবেষণাকারীর		
এবং তার গবেষণার সমন্বয়কারীর সাথে এই গবেষণার পদ্ধতি সম্পর্কে অথব	া যে কোন প্রশ্নের উত্তর জানার জন্য কথা		
বলতে পারবে।			
আমি উপরোক্ত তথ্য গুলো ভালোভাবে জেনে নিজ ইচ্ছায় এই গবেষনায় অংশ	গ্রহন করছি।		
অংশগ্রহনকারীর স্বাক্ষর/টিপসই	তারিখ:		

অংশগ্রহনকারীর স্বাক্ষর/টিপসই	তারিখ:
গবেষণাকারীর স্বাক্ষর	তারিখ:
1911 (11)(10) 3(10)	
সাক্ষ্য প্রধানকারীর স্বাক্ষর/ টিপসই	তারিখ:

### <u>Appendix I</u> Semi-structured Questionnaire (English)

Objective	Main Question	Sub question
1: To explore participants understanding about occupational engagement contributing to well-being after SCI.	1. How would you like to explain or describe your occupational engagement in your own view?	<ol> <li>Do you follow a daily routine? If yes, How do you manage your daily activities according to daily routine?</li> <li>Why these activities are meaningful to you or your life?</li> <li>Are you a student or engaged to any income generating activities? If yes then how do you expense it?</li> </ol>
2: To explore their	1. How satisfactory	4. How satisfied are you with your daily engagement in different activities (self-care, productivity, leisure) with 0-10 scale? Please explain.  1. How satisfied are you with your
understandings about well- being after SCI	level of performance do you play with your	personal relationships? How it influence your occupational engagement?
	daily activities?	2. How your physical and mental Health influence occupational engagement?
		3. What about your financial situation?
		4. How about your personal relationship with your family?
		Could you please tell me more?
		Why your relation is good/bad?  5. Considering all these how satisfied are you with your occupational engagement.
<b>3:</b> Identify the importance of	3. What do you	1. How satisfied are you with your
daily occupations connected	think How the	daily participation according to 0-
with subjective well-being	occupational engagements	10 scale? Please explain elaborately.
	enhance health and	2. How satisfied are you with your
	well being	spirituality or religion? Explain in details. Rate with 0-10 scale.

		2 How do you feel if you
		3. How do you feel if you
		can/can't perform your
		daily occupation?
		4. How satisfied are you
		whatever you have
		achieved in your life till
		now according to 0-10
		scale?
<b>4:</b> To explore the challenges	4. What are the challenges	1. Do you feel any
of person with SCI to	you face while performing	challenges during your
involve in occupation after	your daily occupations?	occupational engagement?
completion of Rehabilitation	Jan an Janaa Janaa	If yes then what are the
according to their opinion.		challenges? If no, in which
decording to their opinion.		activities you need help
		from your family & how
		much supportive they are to
		you?
		2. How satisfied are you
		· · · · · · · · · · · · · · · · · · ·
		being a part of your
		society? Is there any
		challenges? Explain those.
		3. Can you perform all your
		daily occupations? If yes
		then what activities can you
		perform? If no, in which
		activities you need help
		from your family and how
		much supportive they are to
		you?
		4. Overall what you think
		How the occupational
		engagement hamper or
		encourage to your health
		and well-being?
		5. How satisfied are you
		with your personal safety.
		with your personal safety.

# Appendix J

# Semi-structured Questionnaire (Bengali)

### আপনি কেমন আছেন ?

মূল প্রশ্ন	প্রশ
১। কাজে অংশগ্রহণ কে আপনি নিজের ভাষায় কিভাবে ব্যাখ্যা করবেন ?	১। আপনার কি কোন দৈনন্দিন কাজের রুটিন আছে ? যদি থাকে, তবে আপনি কিভাবে আপনার দৈনন্দিন কাজের রুটিন মেনে চলেন ? ২। এই কাজ আপনার কাছে কেন প্রয়োজনীয়/অর্থপূ্ণ ? ৩। আপনি কি ছাত্র /কোন আয় উপার্জনিক কাজে নিয়োজিত ? যদি থাকেন তবে সেটা আপনি কিভাবে ব্যয় করেন ? ৪। দৈনন্দিন কাজে অংশগ্রহণে আপনি কতটুকু সম্ভুষ্ট, ০-১০ ক্ষেলে ? (নিজের কাজ, অবসর যাপন ও উপার্জন মূলক কাজ) বিস্তারিত বলুন।
২। সামগ্রিক সবকিছু বিবেচনা করে আপনি কতটুকু ভালো আছেন ? এবং এই ভালো থাকা আপনি কিভাবে বর্ণনা করবেন ?	১। আপনি আপনার ব্যাক্তিগত সম্পঁক নিয়ে কতটুকু সদ্ভুষ্ট ? এটা কিভাবে আপনার কাজে অংশগ্রহণে প্রভাব ফেলে ? ২। কিভাবে শারিরীক ও মানসিকতা স্বাস্থ্য আপনার কাজে অংশগ্রহণে প্রভাব ফেলে ? ৩। আপনার আর্থিক অবস্থা কেমন ? ৪। আপনার পারিবারিক সম্পঁক কেমন ? আপনি একটু বিন্তারিত বলেন। কেন সম্পঁক টা ভালো/খারাপ ? ৫। সামগ্রিক সবকিছু চিন্তা করে দৈনন্দিন কাজে অংশগ্রহণে আপনি কতটুকু স্বাচ্ছ্যন্দ্য অনুভব করেছেন ?
৩। ০-১০ ক্ষেলের মাধ্যমে বিভিন্ন কাজে অংশগ্রহণ করা আপনার মতে কতটুকু জরুরি ? এবং কেন বিস্তারিত বলেন ?	১। কাজে অংশগ্রহণে আপনি কত্টুকু সম্ভুষ্ট ? ০-১০ ক্ষেলে বলুন। ২। আপনি আপনার র্ধম /আধ্যাত্মিকতা নিয়ে কত্টুকু সম্ভুষ্ট ? ০-১০ ক্ষেলে বলুন। ৩। যদি আপনি কোনো কাজ সম্পাদন করতে না পারেন , তাহলে কেমন অনুভব করেন ? ৪। আপনি আপনার জীবনে যা কিছু অর্জন করেছেন তা নিয়ে কত্টুকু সম্ভুষ্ট ? ০-১০ ক্ষেলে বলুন।
<ul> <li>৪। দৈনন্দিন কাজ সম্পাদনের জন্য আপনি কি কি বাধাঁ সম্মুখীন করেন ?</li> </ul>	১। কাজে অংশগ্রহণের জন্য কোন নেতিবাচক প্রভাব বা বাধাঁ অনুভব করেন কিনা ? যদি করে থাকেন, তবে সেগুলো কি কি ? যদি না করে থাকেন, তবে আপনি আপনার পরিবার বা আশেপাশের মানুষ থেকে কেমন সহযোগীতা পান? ২।আপনি আপনাকে সমাজের অংশ হিসেবে কতটুকু সম্ভুষ্ট অনুভব করেন ? যদি কোন বাঁধা অনুভব করেন তবে সেগুলো কি কি ? ৩। আপনি কি আপনার দৈনন্দিন নিজের কাজ নিজে সম্পাদন করতে পারেন ? হাাঁ/না ? যদি হ্যাঁ হয় তবে কি কি কাজ করতে পারেন ? যদি না হয় তবে কোন কোন কাজে আপনার পরিবার থেকে সহায়তা দরকার হয় ? এবং তারা আপনার কাছে কতটুকু সহায়ক বলে আপনি মনে করেন ? ৪। আপনার দৈনন্দিন জীবনের কাজের ধারা আপনার সুস্থতায় কতটুকু ব্যহত/সহযোগিতা করছে বলে আপনি মনে করেন ? ৫। আপনি আপনার নিরাপত্তা নিয়ে কতটুকু সম্ভুষ্ট অনুভব করেন ?