

Lived Experience of Elderly Individuals with Paraplegia: A Qualitative Study



By

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Statement of Authorship

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Dedication

This thesis dedicated to my mom who have supported me throughout my education

Thanks for her endless love, support and encouragement

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List of Abbreviations

ASIA	American Spinal Injury Association
CBR	Community-Based Rehabilitation
CRP	Centre for the Rehabilitation of the Paralysed
GBD	Global Burden of Disease
GMM	The Generalized Method of Moments
LMIC	Low and Middle-Income Country
LTPA	Leisure Time Physical Activity
NTSC	Non-Traumatic Spinal Cord Injury
NHIRD	National Health Insurance Research Database
PWDs	Persons with Disabilities
SCI	Spinal Cord Injury
SCIDAB	Spinal Cord Injuries' Development Association Bangladesh
TB	Tuberculosis
TSCI	Traumatic Spinal Cord Injury
WHO	World Health Organization

Abstract

Background: Spinal cord injury is one of the devastating conditions in the elderly population. Previous studies indicated that the incidence of spinal cord injury are increasing in elderly. Several studies have been conducted on the lived experience of spinal cord injury patients in different age groups. However, few studies have been done on spinal cord injury and older people. There is no published data on spinal cord injury and the persons with elderly in the South Asian region.

Aim: This research explored the lived experience of elderly individuals with paraplegia.

Methods: This study followed the phenomenological approach of qualitative research design. Seven participants were recruited using purposive sampling who had lived in the community for at least two years after completing rehabilitation services and were aged ≥ 60 years. The self-developed interview guide was used to conduct face-to-face, in-depth interviews with participants at their homes. Data were analysed by Braun and Clarke's six steps of thematic analysis.

Results: Participants explained their experience with physical health, psychological health, society, family and productive life. Eight main themes have emerged from data analysis: i. Occupational Role, ii. Physical Health Issues, iii. Emotional Health, iv. Relationships, v. Social Attitude, vi. Access to Fundamental Rights for Persons with Disabilities, vii. Burden of Age and Disability, viii. Resiliency. Each theme has a sub-theme except Burden of Age and Disability, and Resiliency. The findings demonstrate the significance role in family and productive life, physical and emotional health, meaningful relationship with family, relatives and colleagues, different attitude from society, limited access to fundamental rights for persons with disabilities such as healthcare facilities, disability or old age

allowance, safe residence and social participation. Furthermore, the study findings have revealed resilience among the elderly over time, in addition to the burden of older age and disability.

Conclusions: This thesis explored the lived experience of elderly persons with paraplegia. Specialised geriatric care service is essential in rehabilitation centres and community levels for the older persons. Along with geriatric care services, we need to raise awareness for the access of persons with disabilities to fundamental rights in our community.

Keywords: Spinal cord injury, Paraplegia, Elderly, Older adults, Geriatric population.

CHAPTER I: INTRODUCTION

1.1 Background

Spinal Cord Injury (SCI) is a worldwide disabling disorder that affects health conditions such as physical, mental and social well-being. (Pili et al., 2018). The incidence of spinal cord injury is increasing with time, with an annual rate of 15-40 cases per million (Quadir et al., 2017). A study claimed that the incidence rate of spinal cord injury is more in male 86.8%, and the rate of paraplegic patients is 52% in Bangladesh (Rahman et al., 2017). Traumatic spinal cord injury can result in a significant neurological deficit, it which causes morbidity, disability and death (Furlan & Fehlings, 2009). Conversely, Non-traumatic spinal cord injury (NTSCI) results in a high risk of morbidity and reduced quality of everyday life (Buzzell et al., 2019). Spinal Cord Injury (SCI) was primarily identified as a condition in young adults. However, the study also claimed that as many as 20% of all spinal cord injuries occur in people 65 or older (Roth et al., 1992). Recent studies have indicated that the incidence of spinal cord injury in older age group is increasing, and the incidence of spinal cord injury in younger age groups is decreasing over time (Ko, 2022). The classification of the older age group or the older adult depends on individual culture and context. According to WHO, most developed countries have accepted the chronological age of 65 years and above as a definition of an older adult or older population. In United Nation, people aged 60 years and above has been referred as the older population or Elderly. Similarly, the real statistics in Bangladesh is that people aged 60 and over are considered the persons with elderly (Barikdar et al., 2016; Hossain et al., 2015). Studies have shown that spinal cord injuries disproportionately affect men in the elderly.

Approximately 60% of injuries are caused by traumatic falls, but non-traumatic causes have also been documented, including infection, tumors, and drug-related epidural bleeding (Ikpeze & Mesfin, 2017). Despite the life-threatening nature of the condition, studies have reported improvements in survival over the past 40 years in high-income countries than middle-income countries (Bickenbach et al., 2013; Cripps et al., 2010). However, the increased life expectancy among people with SCI means they will live with disabilities longer and raise multiple new problems that can negatively affect their lives (Chan et al., 2000). Studies indicated that the most common physical health conditions of spinal cord injury are pain, neurogenic bowel and bladder, fatigue, and osteoporosis. Some secondary health issues are more frequent in older people with spinal cord injury, such as cardiovascular disease, diabetes, bone mineral density loss, fatigue and respiratory complications or infections (Jørgensen et al., 2017). Psychological problems lead to more severe problems; studies claimed that the older adult with spinal cord injuries at higher risk of depression due to secondary symptoms of the condition that are underdiagnosed and untreated (Bombardier et al., 2010). Some studies have reported that social support and relationships such as family, friends, health care providers, and peers can play an essential role in coping with the daily life of a person with spinal cord injury. (Duggan et al., 2016; Geard et al., 2018; Monden et al., 2014). Although a number of studies have been conducted on the lived experiences of persons with SCI. Most of these studies were conducted high-income countries in North America, Europe, and Asia. Limited research has been conducted in low middle-income countries (LMIC) to explore the experiences of persons with spinal cord injury. (Fuseini et al., 2019). Also, studies on the lived experience of spinal cord injury show variation between different age groups of the population. Where

limited study has been done on the elderly persons with spinal cord injury. Even there is no published data on spinal cord injury and the persons with elderly in South Asia region. Furthermore, the student researcher, based on her clinical placement, observed that the elderly persons with paraplegia experiences different physical, psychological, social and family issues. Based on this observation, it sought to know how the elderly paraplegic patient experience living with the community after discharge from hospital-based rehabilitation programs.

1.2 Justification of the Study

A person with a spinal cord injury receives a long-term rehab service from the rehabilitation centre. After discharge from the rehab centre, patients re-integrate into the home and community. The lived experiences of community-dwelling spinal cord injury patients vary by age, gender, type of injury, economic and cultural context. Several studies have been conducted on people of different ages with spinal cord injury in the community, but the area of research in the elderly persons with spinal cord injury are still unknown. It is, therefore, essential to know how the older people with paraplegia experience living in the community. If we explore the lived experience of persons with elderly age group, it can provide us new information about their physical, psychological and social experience in the community. These will help to formulate new guidelines for intervention, rehabilitation and community care in the occupational therapy geriatric care service for paraplegic patients. On the other hand, by exploring family relationships, we can improve our knowledge of client and family education which is part of patient advocacy.

In Bangladesh, however, no studies have been published on the lived experiences of older paraplegic patients. By conducting this study, we can explore new information about older paraplegic spinal cord injury patients in Bangladesh.

1.3 Operational Definition

1.3.1 Spinal Cord Injury: The term ‘spinal cord injury’ refers to damage to the spinal cord resulting from trauma (e.g. a car crash) or disease or degeneration (e.g. cancer). There is no reliable global prevalence estimate, but the estimated annual global incidence is 40 to 80 cases per million population. Up to 90% of these cases are due to traumatic causes, though the proportion of non-traumatic spinal cord injuries is growing. (WHO)

1.3.2 Paraplegia: This term refers to motor and sensory function loss or impairment in the thoracic, lumbar, or sacral (not cervical) segments, secondary to the injuries of neural structures in the spinal canal. In paraplegia, arm functions are protected. The trunk, legs, and pelvic organs may be affected depending on the injury level. Moreover, this term is used for cauda equine and conus medullaris injuries. It does not include lumbosacral plexus lesions or peripheral nerve injuries outside the neural canal (Erhan, 2015).

1.3.3 The elderly or Older Adults: Most people above 60 years of age are considered ‘old’. Those 60 years and above make up the elderly section of any population. These age limit also applies to Bangladesh (Barikdar et al., 2016).

1.4 Study Question

What are the lived experience of elderly individuals with paraplegia?

1.4.1 Aim

The study aims to explore the lived experience of elderly individuals with paraplegia.

1.4.2 Objectives

- i. To explore the physical experience of elderly persons with paraplegia
- ii. To explore the psychological experience of elderly persons with paraplegia
- iii. To explore the social experience of elderly persons with paraplegia
- iv. To explore family relationships of elderly persons with paraplegia

CHAPTER II: LITERATURE REVIEW

This literature review chapter is the overview of the findings of some articles on the experience of elderly paraplegic patients in terms of physical, mental, social, family relationships and employment.

2.1 Spinal Cord injury and Persons with Elderly

People with older spinal cord injuries are increasing over time. In 2017, Molton and Yorkston reported that in Western countries, 30% or 40% of people with spinal cord injuries are over 65 years old, even as the proportion of middle-aged or older people with injuries is increasing daily in Eastern countries. A retrospective cohort study was conducted to estimate the incidence, prevalence and life expectancy of persons with spinal cord injury (SCI) by location, sex, age, site of injury and socio-demographic index (SDI) based on data from the Global Burden of Disease (GBD) Study 2019. Estimation was produced by the Bayesian meta-regression tool, DisMod-MR2.1. They found that the incidence and burden of spinal cord injury have increased over the past 30 years, where men and older people are more affected than women and younger people (Weizhong et al., 2022). The limitation of the study was that it did not mention the experiences of male and the elderly survivors of spinal cord injuries that burdened their everyday lives. In Canada in 2014, A systemic search was conducted by Singh and colleagues to determine the impact of SCI and summarised the literature by reporting on the incidence or prevalence of SCI. They found that the incidence, prevalence, and causation of SCI are different between developing and developed countries, whereas the most common traumatic SCI cause falls in the elderly population (Singh et al., 2022). A limitation of the study is that they collect

more data from European countries than Asian countries, which results do not represent our country.

2.2 Health of the Persons with Elderly Paraplegia

This literature review section covers the physical and mental health issues of older paraplegic patients.

2.2.1 Physical Health

Literature indicates that the person with elderly paraplegia experiences several physical health issues such as pain, neurogenic bowel and bladder, fatigue, osteoporosis, stroke, coronary heart disease, chronic heart failure, arrhythmia, diabetes, bone mineral density loss, asthma, bronchitis, pressure ulcer, carpal tunnel syndrome, chronic obstructive pulmonary disease, deep venous thrombosis, pulmonary embolism, autonomic dysreflexia, kidney stone, hypertension, infection, gastrointestinal issues, loss of strength and endurance, hypertrophy, hearing impairment, orthopaedic impairment, cataracts, sinusitis, tinnitus, and visual impairment (Charlifue et al., 2004; E.Villanueva, 2000; Jörgensen et al., 2016; Krassioukov et al., 2003; McGlinchey-Berroth et al., 1995). A retrospective cross-sectional study was conducted among participants 5 to 25 years post-injury to identify the impact of age, age at injury, years of post-injury, and changes in the severity of injury over time in selected physical and psychosocial outcomes of people ageing with spinal cord injury (SCI). Participants were recruited from a regional Model Spinal Cord Injury System of Downey in California who received initial rehabilitation and regular follow-up from 1973 to 1998 (Charlifue et al., 2004). They found that the frequency of re-hospitalisations decreased, and the number of pressure ulcers increased as time passed. Although they had taken 5 to 25 years of post-injury data of mixed age cohort, they did not

specify the data of older age group participants. In England, a cross-sectional study was conducted to report the demographic and clinical characteristics of an initial cohort of ageing spinal cord-injured persons. In the study, 510 participants were recruited from West Roxbury DVA Medical Center, and the age range was from 18 to 84 years; twenty-three percent of patients were at least 65 years of age (McGlinchey-Berroth et al., 1995). They found several health issues are more prevalent in elderly patients with spinal cord injuries. These included carpal tunnel syndrome, chronic obstructive pulmonary disease, myocardial infarction, diabetes, kidney stones, pressure ulcers and hypertension. Although this study considered the older person at least 65 years old, in the South Asian subcontinent, the persons elderly are considered 60 years or older. In Canada, another retrospective study was conducted to evaluate the effect of age on clinical outcomes after managing acute traumatic SCI in an acute care unit by a multidisciplinary team. A total of 58 Participants between the ages of 17 and 89 were recruited from Toronto Western Hospital from January 1998 to December 2000 (Krassioukov et al., 2003). They reported that the co-morbidities were more frequent in the elderly group. However, the incidence of secondary complications was similar in younger and elderly groups, where the most common secondary complications were infections, pressure sores, and cardiovascular complications. Although the study did not mention the sampling strategy, the sample size was not large enough.

2.2.2 Mental Health

In this section, the principal mental health findings are depression, anxiety, dementia, and delirium (Bonanno et al., 2012; Cheung et al., 2013; Huang et al., 2017; Jørgensen et al., 2017). A longitudinal study aimed to investigate longitudinal trajectories of depression and

anxiety symptoms following spinal cord injury (SCI). A total of 233 newly injured participants were recruited from six European countries, such as British, Swiss, Swedish, German, Austrian, and Irish spinal centres, where participants were injured between the ages of 16 and 83. They found that depression and anxiety symptoms revealed three similar latent classes: a resilient pattern of stable low symptoms, a pattern of high symptoms followed by improvement (recovery), and delayed symptom elevations (Bonanno et al., 2012). The limitation of the study is that participants were mixed age cohort, and The Generalized Method of Moments (GMM) approach was applied in the study, which is well suited for field studies. In Sweden, a cross-sectional study aimed to assess the presence of depressive symptoms among older participants with long-term spinal cord injury and investigate the association with socio-demographic and injury characteristics, and determine potential factors. A total of 122 participants were recruited from the community of Sweden where the age range was 50 to 89. They reported that 29% have clinically relevant depressive symptoms, and 5% have probable depression; the sense of coherence, the coping strategy acceptance, neuropathic pain and leisure-time physical activity explained 53% of the variance in depressive symptoms (Jørgensen et al., 2017). The limitation of the study is that they used a self-reported assessment tool for LTPA and did not mention the sampling strategy. In Taiwan, A longitudinal study aimed to evaluate the incidence of dementia in patients with SCI. All participants were >18 years old and recruited from the National Health Insurance Research Database (NHIRD) list, where 941 participants with SCI and 5,060 participants without SCI were selected by random sampling. They found that patients with SCI had a significantly higher risk of dementia than did those without SCI (Huang et al., 2017). In this study, they took the data of a mixed-

age cohort but did not specify the data of older age group participants. In Canada, A nested case-control study was conducted to characterise the onset, risk factors, and impact of delirium in patients with traumatic SCI. One hundred ninety-three adult traumatic SCI patients who were discharged from the Acute Spinal Unit of a quaternary referral center were recruited. They reported that Thirty-four (17.7%) of patients between the age of 55 to 76 years experienced delirium during acute care hospitalisation, and elderly patients who sustain a TSCI and have a low motor score on admission are at increased risk of delirium (Cheung et al., 2013). Although the study sample size was not large enough, the study was conducted on a single-institution basis.

2.3 Community Life of the Persons with Elderly SCI

This section of the literature review covers the community life of the older person with SCI, such as their family, social integration, accessibility, social support and employment.

2.3.1 Family

Family relationships strongly influence the life satisfaction of people with spinal cord injuries. A longitudinal study was conducted with the aim of life satisfaction one-year post-discharge for persons with a spinal cord injury (SCI) or traumatic brain injury (TBI). One hundred seventy-five participants were discharged from acute care and recruited for the study, where 137 were TBI and 38 were SCI. They found that closeness to family, satisfaction with the level of family activities, and blaming oneself for the injury were the three most important variables determining life satisfaction in people with spinal cord injuries (Warren et al., 1996). In the limitation of study, the age range of the participants was not mentioned.

2.3.2 Social Integration

Social participation is a vital determinant of well-being. People with elderly SCI are restricted from social participation opportunities which may hamper their well-being. A cross-sectional study was conducted with the aim of participation and life satisfaction levels in individuals with SCI aged 65 years or older and to analyse differences in participation and life satisfaction scores between individuals injured before or after 50. A total of 128 participants were recruited who were at least 65 years old, where participation was measured by the Utrecht Scale for Evaluation-Participation and satisfaction was measured by five items of the World Health Organization Quality of Life abbreviated form. They found that participants who were injured before 50 showed similar levels of functional status and numbers of secondary health conditions but higher participation and life satisfaction scores by comparing with participants who were injured at an older age (Post & Reinhardt, 2015). The study did not reveal the indications for worsening participation or life satisfaction. In Canada, a Critical review was conducted with the aim of social participation of persons with elderly SCI, including the benefits and factors associated with it and the measures used to evaluate it. The literature review was conducted using Ovid Medline (1996–2008), CINAHL (1982–2008) and PsycINFO (1985–2008). They found that studies on older people have focused on the benefits of social participation and the associated factors. Studies have also examined the personal and environmental factors that influence the social participation of older persons. Several instruments exist to measure social participation; however, none were developed specifically for the persons with elderly (Dahan-Oliel et al., 2008). It was recommended that more research need to conduct in the area of social participation in persons with elderly SCI.

2.3.3 Accessibility

Accessibility is essential for independent living and participation, which is affected by the persons with elderly SCI. In Sweden, A cross-sectional study was conducted to describe the housing situation and aspects of participation among older people living with long-standing spinal cord injury (SCI) and how housing accessibility is associated with aspects of participation. A total of 123 participants were recruited from the community who was in elderly (≥ 50 years), and three groups of SCI severity were formed using the American Spinal Injury Association (ASIA) Impairment Scale. They reported that housing adaptations and environmental barriers were common and differed between SCI severity groups; accessibility problems were associated with less participation (Norin et al., 2017). The limitation of the study was that the sample size was not large enough.

2.3.4 Social Support

Social support is essential things for persons with elderly spinal cord injury (SCI). In Switzerland, A comparative study of self-reported surveys was conducted to compare the individuals living with spinal cord injury in Switzerland to the general population regarding mental health, quality of life, self-efficacy, and social support. Participants were recruited from the community who were 16 years old or above. They found that Individuals with SCI had significantly higher psychological distress and poorer mental health, vitality, energy, and quality of life, lower self-efficacy and relationship satisfaction, lived more frequently alone, and were more frequently single than the general population (Carrard et al., 2021). In the study, the number of participants was not mentioned, and the data findings were mixed age cohort; they did not specify the data of older age group participants. Another comparative study was conducted in Canada to explain the effect of age and

disability on social support by studying the support system on stroke and SCI groups of adults with disabilities. Total of 210 individuals with ages ranging from 18 to 70. Participants of the stroke group were recruited from those consecutively discharged from community occupational therapy associates and home care programs from metropolitan, and the SCI group was recruited from those who were follow-up from five major Ontario spinal rehabilitation centres. The study's findings were that spinal cord injuries had more of all three types of support (instrumental, informational, and emotional) than those with strokes (McColl et al., 1994). In the study, the findings of the data were mixed age cohort; they did not specify the data of older age group participants. A longitudinal study aimed to describe the support systems of a multicenter sample of people with long-standing spinal cord injuries (SCIs) and to explore the effects of age, duration of injury, problems, demographics, and well-being on reporting of social support. A total of 290 participants with an average age of 57 years were recruited from four large, well-established databases in the United Kingdom and Canada. They reported that informational support was less available than instrumental or emotional support. Age has a direct negative effect on satisfaction with social support but an indirect positive effect on the availability of support mediated by well-being. On the other hand, disability indirectly negatively affects satisfaction, mediated by problems (McColl et al., 2001). In the study, the sampling strategy was not mentioned.

2.3.5 Employment

Employment is another vital thing for financial and psychosocial well-being. In Canada, A study was conducted to compare the employment participation of middle-aged and older people with SCI and to examine the association between employment and demographic

and health factors, SCI-related needs, and social role participation at the two life phases. A total of 1,323 participants, middle-aged (18-54 years) and older-aged (55-64 years), were recruited from a larger Canadian community and compared to middle-aged and older aged. The study's findings were that one-third of participants with SCI were working post-injury (32%), and 62% of respondents declined their pre-injury job. Participants were likelier to work in less physically demanding job sectors, including business/administration or health/science/teaching. Another difference showed that middle-aged adults were more likely to be employed post-injury (36%) when compared to older respondents (12% employed), who were more likely to report being retired (43%) (Jetha et al., 2014). The study highlighted the comparison of both groups about employment but did not indicate job-related issues and the performance of older people.

2.4 Key Gaps of the Study

- ▶ Most published literature about spinal cord injury are conducted with the young generation and mixed-aged cohort, which is the most significant evidence gap. Few literature studies were conducted on the elderly population with SCI, where the age range for the persons with elderly were ≥ 65 . However, In the South Asian subcontinent, the persons with elderly are considered to be 60 years or older.
- ▶ The time of most publications regarding spinal cord injury and elderly persons between 1995 to 2017.
- ▶ Most of the studies of the elderly spinal cord injury patients were comparative studies where the elderly SCI population was compared with younger SCI or the country's general population. The limited research was conducted only on persons with elderly paraplegic patients.

- ▶ Several studies have found that was conducted on retrospective study design where the findings were older more than 25 years from now.
- ▶ Some published literature did not mention their sampling strategy from the whole population.
- ▶ Most of the study settings of published literature were hospital-based rather than community.
- ▶ Most of the study on persons with elderly paraplegia was conducted in Canada, the U.S., Sweden, England, and Switzerland. However, no published evidence exists in the South Asia subcontinent or even Bangladesh.

CHAPTER III: METHODOLOGY

3.1 Study Design

3.1.1 Study Method

The student researcher used the qualitative research method to understand how paraplegic male patient experience their life in old age. It involves collecting and analysing non-numerical data to understand concepts, opinions, or experiences. Qualitative research can be used to gather in-depth insights (Bhandari, 2020).

In qualitative research design, researcher investigate the social context that influence the subjective experiences of human being over time (Dew, 2007). Qualitative research enables us to make sense of reality, to describe and explain the social world and to develop explanatory models and theories. It is the primary means by which the theoretical foundations of social sciences may be constructed or re-examined (Morse et al., 1996). It help to prioritises people's word or stories, instead of the "science of numbers", as in quantitative studies (Liamputtong, 2013; Patton, 2015).

3.1.2 Study Approach

The student researcher followed the phenomenological approach to conduct this study. Because the phenomenological approach can broaden our understanding of the complex phenomena involved in learning, behaviour and communication. Moreover, it helps us to understand the meaning of a person's perception, knowledge and lived experience (Neubauer et al., 2019). The phenomenological approach offers the opportunity to understand the meaning of a phenomenon as it really is for the individual. This approach reveals the hidden meanings of the phenomenon through study. The findings of the

phenomenological studies can provide a more detailed understanding of the phenomenon and provide evidence for improving health care practice (Clarke, 2009). As such, the phenomenological design was deemed appropriate for this study and helped the student researcher to focus on the individual lived experience of the person with elderly paraplegia.

3.3 Study Setting and Period

3.3.1 Study Setting

The participants who participated in the study were from their respective communities. Data was collected from different communities in Savar Upazila, such as Shimulia, Dhamshona, Pathaliya, Yarpur, Ashulia, Birulia, Tetuljhora, Bongaon, Amin Bazar, Kaundia, Vakurta and Savar union. After completing the rehabilitation program from CRP, participants are living in their homes and own communities. The student researcher travelled to each participant's home following a pre-scheduled time to conduct interviews.

3.3.2 Study Period

The time frame for conducting the study was April 2022-March 2023.

3.4 Study Participants

3.4.1 Sampling Techniques

The student researcher selected a purposive sampling process to collect the data. Participants were selected to conduct this study based on inclusion and exclusion criteria. Purposive sampling is a non-probability sampling technique. It is also known as judgmental, selective or subjective sampling (Leardcom, 2019). Purposive sampling is a strategy in which persons or events are selected deliberately to provide important information. The researcher includes participants in the sample because they believe they warrant inclusion (Taherdoost, 2016).

3.4.2 Inclusion Criteria

i. Participants aged 60 years or above during data collection and living in the community for at least two years.

ii. Male paraplegic spinal cord injury patient

The United Nations refers to older persons as 60 years and above and is used as the real statistics in Bangladesh (Hossain et al., 2015).

Student researchers were unable to reach female paraplegic patients aged 60 and older. So, the study was conducted on male patients to gain in-depth knowledge in this unexplored area.

3.4.3 Exclusion Criteria

i. Paraplegic patient who had a history of diagnosed mental illness and brain injury. Diagnosed by a doctor or psychiatrist or recorded in the patient document.

ii. Paraplegic patient with severe hearing problems diagnosed by a doctor or recorded in the patient document.

3.4.4 Participant Overview

In this study, all participants were paraplegic male patients who were aged above 60 years. All participants have been living in the community for more than two years. The student researcher collected the data from eight participants. The field test was conducted on one participant, and the other seven participants participated in the main study.

Table1: Participant's Overview

Pseudo name	Age at injury	Age at interview	Type of injury	Date of incident	Mobility device	Current job (if any)
Abraham	60	76	Incomplete Paraplegia	02-12-06	Independent walking	None
Amir	14	61	Complete Paraplegia	24-06-75	W/C	Carpenter
Ikhlas	55	62	Incomplete Paraplegia	25-05-15	W/C	Business
Kafi	51	65	Incomplete Paraplegia	15-07-08	Walking stick	None
Krishna	21	63	Incomplete Paraplegia	10-03-80	W/C	None
Mokbul	54	61	Complete Paraplegia	02-06-15	W/C	None
Motiur	21	63	Complete Paraplegia	30-12-80	W/C	Business

3.5 Ethical Consideration

Ethical considerations were maintained according to the Declaration of Helsinki Act's guidelines,

- At first student researcher has taken permission from the Institutional Ethical Review Board of BHPI through the Department of Occupational Therapy, BHPI. The ethical clearance number of this study is CRP/BHPI/IRB/09/22/642.

- The participant was informed about the study through the Participant Information Sheet, and the student researcher took the participant's written consent before conducting the interview.
- Participants were informed about the withdrawal process. Any interviewers could withdraw their participation within one month from the interview date.
- The student researcher ensured and maintained the confidentiality of the participants. Only the student researcher and the supervisor had access to the interviews, as clearly stated in the Participant information Sheet.
- There was no bias in selecting participants, as the study participants were selected based on inclusion and exclusion criteria.
- There was no power or unequal relationship in the study
- The student researcher cleared the benefit of the study to each participant.
- There was no risk or hazard by physically, mentally or economically to the participants for providing the information.
- The student researcher was available for any study-related questions or inquiries from the participant.

See the Appendix B for the Written Consent Form, Withdrawal Form and Participant Information Sheet.

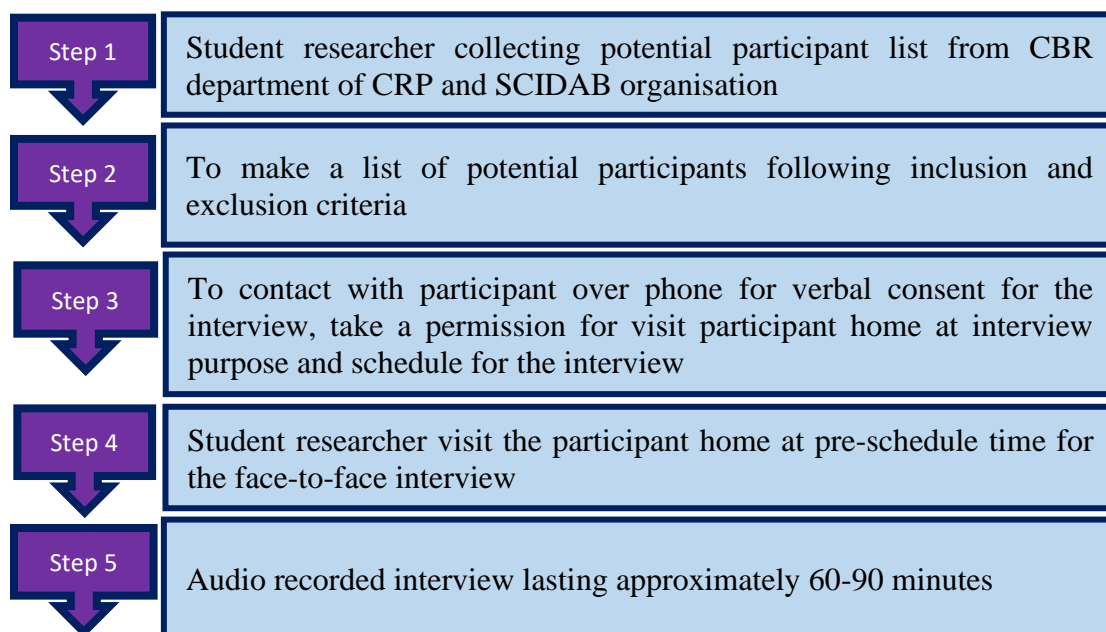
3.6 Data Collection Process

3.6.1 Participants Recruitment Process

At first, the student researcher collected the list of participants from the Community-Based Rehabilitation (CBR) department of CRP and Spinal Cord Injuries' Development Association Bangladesh (SCIDAB), the organisation for a person with spinal cord

injuries. Then Student researcher will list potential participants following inclusion and exclusion criteria. After making a list, the student researcher will contact the participant over the phone and explain very clearly, using the participant information sheet, what the study required of participants who agreed to participate, such as participation in a semi-structured in-depth interview with permission of audio recording, lasting 60-90 minutes. After explaining the study over the telephone, the student researcher takes verbal consent from participants interested in participating in the interview, takes permission to visit the participant's home for interview purposes and fixes a date and time with the participant. Below is a diagram of the flow of participant recruitment:

Figure 1: Steps of Participant Recruitment



3.6.2 Non-participant

The student researcher was able to contact a total of 20 potential participants by telephone according to the inclusion and exclusion criteria. Three out of the twenty participants refused to participate in the study due to their current illness. Another two participants died

which were reported by family members during phone calls. Total 15 participant was agreed to take a part of the study.

3.6.3 Data Collection Method

3.6.3.1 In-depth Semi-Structured Interview

To conduct this study, the student researcher conducted face-to-face, in-depth semi-structured interviews.

The in-depth semi-structured interview process is an effective method for collecting qualitative open-ended data, to explore participants thoughts, feelings and beliefs about a particular topic, to understand deeply into personal and sensitive issues (Jamshed, 2014). It also allowed the researchers to have more direct contact with the participants, and it is through this interaction between interviewer and interviewee that knowledge is produced (Kvale & Brinkmann, 2009).

Firstly, The student researcher visited the participants' homes to collect data following the pre-scheduled time. Though the participant lived with their family members, the student researcher also discussed the aim and significance of the study with them, which helped to build loyalty among the student researcher and family members. In some cases, close family members express their opinions. The student researcher took notes of those points and included them with field notes. The confidentiality issue was explained to family members as the interview was conducted from home. The family members allowed the student researcher to interview in a separate room. In this way, confidentiality was maintained among participants. The family members were cooperative during the entire interview process.

Before starting the interview, the student researcher thanked the participant for agreeing to participate in the study. Then introduced herself to the participants, explained the research topic and its purpose, and allowed participants to ask questions. The student researcher explains the expected length of the interview and an overview of the sample questions to explain the aim and objectives of the study to the participants. It helped the participants feel self-assured that there were no right or wrong answers to open-ended questions in the interview. This approach helped to build a good rapport between the student researcher and participant and created a comfortable environment during the interview. The student researcher provided the participant information sheet and consent form to the participant. Once they consented to the interview, the student researcher conducted the interview, followed by the guide. Every participant's interview takes time between 60-90 minutes. The whole interview was recorded on a mobile phone. Before starting the interview, the student researcher ensured that the device was kept in flight mode to avoid any calls or messages that could interrupt the audio recording. The entire interview was conducted in Bengali. The student researcher asked all Bengali questions, which helped understand each participant. Although Bengali is the native language of Bangladesh, people from different areas use some local languages. The student researcher was careful about active listening and rechecked the meaning of the participant's local languages.

3.6.3.2 Field Note and Reflective Diary

The other data source was the student researcher's field notes and reflective diary. The field note refers to notes created by the researcher while conducting a field study to remember and record an observation's behaviours, activities, events, and other features (Schwandt, 2015). The student researcher took field notes in each interview and kept a reflection note

after every interview. Field notes and a reflective diary were written in a notebook. Field notes recorded participants' emotions, behaviours, expressions, home environment and the important information that provided by family members. In the reflective diary are included the researcher's personal reaction and thoughts after each interview. Field notes and reflective diary helped the student researcher in analysing the data. These were also used to write short narratives of each interview such as history of injury, home environment and overall current status (See Appendix E for the narratives).

3.6.4 Data Collection Instrument

3.6.4.1 Self-developed Interview Guide

A self-developed interview guide was used where open-ended questions were asked for data collection. At first, student researchers generate ideas from different literature for developing interview guides. The student researcher focused on each objective and covered the physical experience, psychological experience, social experience and family relationship to develop the interview question. Some demographic questions have been added to the interview guide. Since the Bengali language was understandable to the interview participants, the student researcher converted the English interview guide into Bengali. After the field test, some additional questions about the participant's current job were added to the initial interview guide and converted into a modified one. Participants with a current job or source of self-income were asked additional job-related questions. Finally, the modified interview guide was converted from Bengali to English.

See the Appendix C for Modified Interview Guide

3.6.4.2 Field Test

A field test was conducted with a participant. It was necessary to carry out a field test before starting the final data collection. Field tests help the researcher avoid ambiguity, adjust the word choice and refine the question for data collection. Before starting the interview, the student researcher informed the participant about the aim and objective of the study. During the interview, the student researcher became aware of which part was difficult to understand for the participant. The student researcher asked some additional questions that needed to be asked but were not mentioned in the interview guide. The entire interview was audio recorded on a mobile phone for further analysis. After the interviews, the student researcher analysed the audio-recorded interview to refine the questions and added additional questions to the interview guide. Finally, the interview guide was modified in Bengali and English.

See the Appendix C for the Modified Bengali and English Interview Guide.

3.6.5 Data Saturation

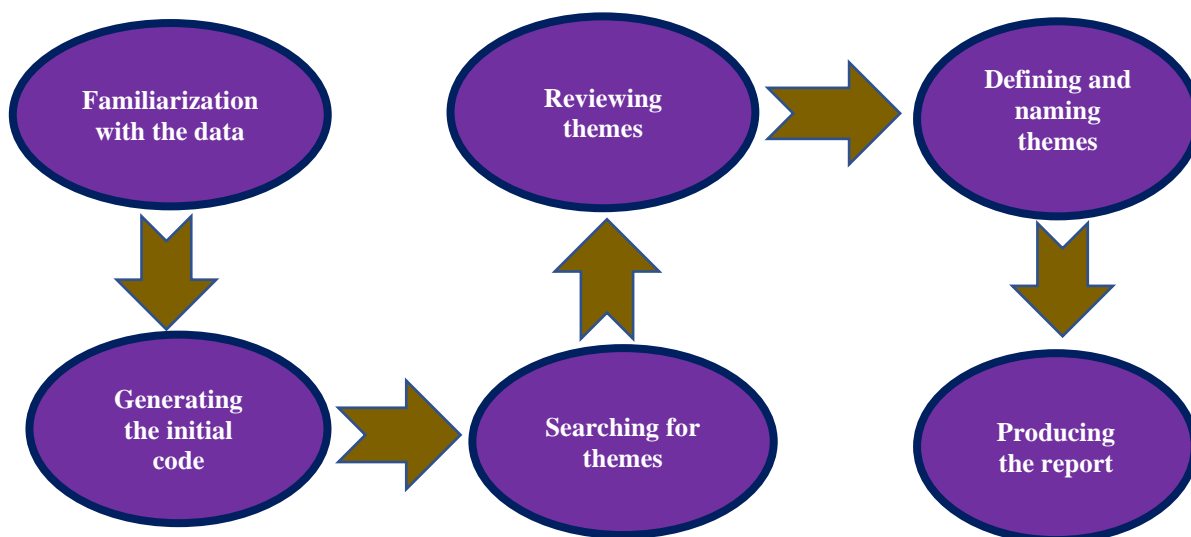
Data saturation means when all the needed data have been collected and there is no any new relevant information or data that can be collected from the respondents or subjects of the study (Fusch et al., 2018). Data were saturated between the sixth and seventh participants in the study where information or data were similar to each other. For that reason, the student researcher stopped data collection after taking data from the seventh participant.

3.7 Data Management and Analysis

The student researcher analysed the data according to Braun and Clarke's six steps of thematic analysis (Clarke & Braun, 2016). Thematic analysis is a method for analysing

qualitative data that entails searching across a data set to identify, analyse, and report repeated patterns (Braun & Clarke, 2006). Researchers have suggested that thematic analysis is an excellent first analytic method for novice qualitative researchers to master (Braun & Clarke, 2006; Clarke & Braun, 2016; Nowell et al., 2017). Six steps of Braun and Clarke's are :

Figure 2: Braun and Clarke's Six Steps of Thematic Analysis



Step1: Familiarization with the data

At first, the student researcher got familiarised with the data by taking interviews, transcribing audio data verbatim in Bengali and translating it into Bengali to English. Then translated transcripts were used for analysing data. she thoroughly read first to last to gain an in-depth understanding of the subjective meaning and pattern of data. Highlighted the interesting points of the translated file.

Step 2: Generating the initial code

In the second step, the student researcher generates the initial code by writing the meaning of highlighted interesting points of the participants. The student researcher and experienced

subject teacher discussed how to develop the initial codes. All the interesting feature were coded in a systemic way. The student researcher used the same word while writing the initial code for the similar response of different participants.

Step3: Searching for themes

In the third step, all the similar or standard codes are grouped together to find out the potential themes. Similar ideas were written on each column of a table for grouped easily, helped to find potential themes. This process was done for each interview.

Step 4: Reviewing themes

In the fourth step, the student researcher generated initial theme and discussed this with the experienced subject teacher. The discussion assisted in identifying the possible themes and sub-themes. At this stage, Seven potential themes were identified, with a few sub-themes.

Step 5: Defining and naming themes

In this step, the student researcher refined and reviewed the theme by justifying enough data, which resulted in eight themes at the final stage. The student researcher generated clear name and definition for each themes and sub-themes by discussing with subject teacher. The reader can get the idea by the theme's name and understand what is explained in the theme.

Step 6: Producing the report

In the final step, the student researcher started to produce the report, based on the interpretations generated. The report contained the summary of the themes, with quotations from the participants used to understand and clarify subjective message from them.

3.7.1 Triangulation and Member Checking

Investigator triangulation was done in the process of data analysis. Subject teachers were involved with the student researcher throughout the process, checking and refining the data. The student researcher also conducted the member checking after analysing the data. Member checking was conducted based on the “participative member checking approach”. According to Doyle (2007), the participative member-checking approach is helpful for member-checking in older participants. First, the student researcher contacted each participant by phone to request permission to re-visit their home for member checking. Then she re-visits the participant's home at a pre-scheduled time for member checking. Student researchers allow them to choose how the member checking would be processed. Participants may read hard copies of transcripts or have someone read to them. Then ask to check them (Does this match their experience? Want to change anything? Want to add anything?) transcript file. After checking the transcript file, each participant's signature is on the transcript file. The student researcher also gave participants a hard copy of the transcript file before leaving the participant's homes.

3.8 Trustworthiness and Rigor

Trustworthiness was maintained by following methodological and interpretive rigour (Fossey et al., 2002). The steps are mentioned in the bullet points:

3.8.1 Methodological Rigor

► Congruence

As this study aimed to identify lived experience, the phenomenological approach of the qualitative design was a perfect fit to achieve the aim and objectives. (See the section of 3.2 Study Design from the list.)

► Responsiveness to Social Context

This study was responsive to social context; the student researcher had direct experience with participants while conducting the interview. The interview was taken in the real-life context of the participant's home. (See the section of 3.3 Study Setting and Period)

► Appropriateness and Adequacy

In the study, a purposive sampling strategy was used to identify the compatible participants for this study. Data were collected through face-to-face interviews. Additionally, field notes were taken during the interview and reflective diary were recorded after the interview, which were used to analysis the data. (See section 3.4.1 Sampling Techniques and 3.6.1 Participant Recruitment Process).

► Transparency

The student researcher was responsible for data collection and analysis in the study. However, experienced subject teachers actively checked the different steps of data analysis. Theme and sub-theme were finally developed by maintaining the consistency of the research question, aim and objectives. (See the point of 3.6 Data Collection Process for more information).

3.8.2 Interpretive Rigor

► Authenticity

Participants' views and voices are presented in verbatim quotation representing the originality of the data. The participants rechecked the demographic data collected from the CRP database to ensure data correction. Member checking or reviewing of the analysis could be done by re-visiting the participant's home after the results have been analysed. (See the section of 3.7 Data Management and Analysis)

► Coherence

The student researcher highlighted the transcript's vital features, talked to the subject teachers about how to apply the meaning of codes, and discussed the data analysis process. Then the student researcher discussed the initial coding, theme and sub-theme with experienced subject teachers. The feedback from subject teachers led to the refinement of the presentation of data findings. (See the section of 3.7 Data Management and Analysis)

► Reciprocity

The reciprocity was maintained by recording the participant's interview and summarising some interview answers to check the researcher's understanding of the interview. The student researcher transcribed each interview verbatim; then, it was translated and kept the data's original meaning. (See the section of 3.7 Data Management and Analysis)

► Typicality

The research was conducted in the context of Bangladesh; people from another country might find it difficult to relate to their context. Although there are similarities between the countries of the South Asian subcontinent in terms of infrastructure. Research reports can be helpful for them.

► Permeability of the Researcher

The student researcher kept the research role transparent. Two subject teachers' engagement has been described in the section on coherence. Their involvement in the study was beneficial for keeping the study unbiased. (See the section of 3.7 Data Management and Analysis)

CHAPTER IV: RESULT

This chapter portrays the detailed findings of this study. Eight main themes emerged from the data analysis: 1. Occupational Role, 2. Physical Health Issues, 3. Emotional Health, 4. Relationships, 5. Social attitude, 6. Access to Fundamental Rights for Persons with Disability, 7. Burden of Age and Disability, and 8. Resiliency. Each theme has a sub-theme except Burden of Age and Disability and Resiliency.

Table 2: Overview of Results

Theme	Sub-theme
1. Occupational Role	Family Role
	Productive Role
2. Physical Health Issues	Secondary Complications Related to SCI
	Co-morbidities
3. Emotional Health	Positive Emotions
	Negative Emotions
4. Relationships	Relationship with family
	Relationship with Relatives
	Relationship with Colleagues
5. Social Attitude	Bullying
	Supportive Attitude
6. Access to Fundamental Rights for Persons with Disabilities	Healthcare Facilities
	Disability or Old Age Allowance
	Safe Residence
	Social Participation
7. Burden of Age and Disability	
8. Resiliency	

4.1 Theme One: Occupational Role

All participants talked about their current occupational roles. Each participant reported their different roles as father, husband, brother, grandfather, employee and trader. These roles have been segregated into two and described below:

4.1.1 Sub-theme One: Family Role

All participant expressed their current family role as a father, husband, brother, or grandfather. Four out of seven participants directly mentioned that there were no significant responsibilities they have now in the family. They have withdrawn from all the responsibilities they had previously performed at a young age. Mr Kafi said:

“I have given up on everything now. I have no role or responsibility in the family. Now I am done. I tell my children always to think I am not in the family. Now you will think that my father is dead.”

Only three participants reported that they still perform all the responsibilities as the head of the family as father, brother, husband and grandfather. Mr Ikhlis said:

“No one in the family live with me. Still, I keep informed of my daughters all the time. I pay their living expenses; I give them money for food and also give them extra pocket money. As a father, I fulfil all my responsibilities for them.”

4.1.2 Sub-theme Two: Productive Role

Three participants reported their roles in productive life as employees in paid jobs and as traders in own businesses. They claimed that work role performance changed over time due to the progression of disability and age. Mr Amir has been working in carpentry for 40 years. He mentioned that:

“In previously, I used to set a target at work of exactly how many wooden designs I

would cut in a certain amount of time. Even my boss told me that you cannot finish the tasks within your target time. I showed my boss that I have completed my tasks before my target time. But now I find it difficult to complete those same tasks at work. Therefore, now I am allowed to do only simple tasks at work such as cutting only plain wood.”

4.2 Theme Two: Physical Health Issue

All participants indicated various physical health problems that they are currently suffering from. They reported chronic conditions as well as multiple physical health complications that progressed in old age due to SCI. Two main sub-themes were identified as follows:

4.2.1 Sub-theme One: Secondary Complication Related to SCI

All participants reported secondary complications that progressed over time and severely affected their daily lives. They talked about complications such as bowel-bladder incontinence, paresthesia, hypertension, loss of appetite, loss of strength and endurance, muscle spasms, deep vein thrombosis, autonomic dysreflexia, pressure sore and sleep disturbance.

Four participants indicated bowel-bladder incontinence as a major complication in old age.

Mr Krishna mentioned that:

“I cannot hold urine. My urine comes out directly when urinary pressure is created. I do not urinate much during the day, very little. But when I sleep at night, if I change my position during sleep, urine comes out automatically.”

Another participant, Mr Amir, said: “Now I cannot eat like before... Earlier, it was easy for me to eat a kilo of meat, but now I cannot eat a single piece of meat.”

4.2.2 Sub-theme Two: Co-morbidities

Participants talked about several co-morbidities that increased in their old age. They reported chronic conditions such as stroke, asthma, heart disease and restlessness, kidney disease, bladder stone and age-related cataract.

Three participants reported their experience of stroke. Mr Kafi mentioned that:

“Hypertension makes me dizzy and sweat profusely. I lose consciousness when my blood pressure rises. One day I was standing on the balcony of the front yard and suddenly fell from the balcony...People die once they have a stroke, and I have an experience of few strokes!”

Another participant, Mr Abraham, mentioned that:

“The most serious problem I have now is chest pain. The left side of the chest feels like someone is stabbing it with a needle... It happens when I walk short distances, like fifteen or twenty minutes. It also happens when I do any heavy work during the day. Then I feel a restlessness in my chest, my body feels weak and my eyes get blurry.”

4.3 Theme Three: Emotional Health

All participant expressed their emotion about what they were currently thinking. They showed their various positive emotion and negative emotions. Most of the participants manifested their negative emotions more than their positive emotions. The two main sub-themes were identified based on their emotion. The related sub-theme is described as follows:

4.3.1 Sub-theme One: Positive Emotions

Five out of the seven participants expressed their current various positive emotions. They talked about their happiness, peace, satisfaction and blissful life in old age. They enjoyed their previous lives, which helped them build age-related acceptance. Mr Motiur talked about his past memories. He mentioned that:

“Remembering the past memories makes me feel ultimate satisfaction. I used to travel alone with a wheelchair and went to different places. I have travelled to different places on my own accord. Like when I went to Sylhet, I did not need anyone's support. Even I also played sports before. It is nice to think about all these things.”

Another participant, Mr Amir, said: “All my happiness revolves around my family. I love it when my children and wife are by my side in anything. That is my absolute peace (Smiling face).”

4.3.2 Sub-theme Two: Negative Emotions

All seven participants expressed their different negative emotions about the current situation. They expressed multiple emotions such as distress about disability and dependency, worried for children and their future, nervousness and fear about physical condition, missing beloved ones, getting hurt by people, worry about poverty, anxious about sick wife, and worry about getting old.

Four participants expressed distressed when talking about their disability and dependent lives. Mr Krishna mentioned that:

“What will my feelings be? (Smile on sad face) I am dependent on others. I had a strength of my own, but now I don't have it. My strength is completely gone now...Earlier, when I went to the office, I got extra money by working overtime

without a salary in per month. My overtime money was enough to support my family. But now, if I need ten takas, I have to ask someone. Everything is now dependent on others.”

Three participants expressed worry about children and their future. Mr Ikhlas said:

“My two sons live with my wife. I used to talk to my children on the phone, but now my wife does not allow me to talk with my children anymore. Lately, I am worried about whether the children's education has been dropped or not.”

4.4 Theme Four: Relationships

All participants talked about their current relationships with different groups of people, such as family members, relatives and colleagues. They expressed supportive and sympathetic attitudes as well as neglect from those close to them as they grew older. The related sub-theme is described as follows:

4.4.1 Sub-theme One: Relationship with Family

Participants reported in their relationship that they face both positive and negative attitudes from their wife, children and siblings. They claimed that relationships change with getting older, either becoming more caring or neglectful than before. Most participants explained that they have a loving and caring relationship with their wives, are always respected as a father by their children, and are beloved brothers to their siblings. When Mr Mokbul talks about his relationship with his wife, he says:

“Allah has given me such a woman as a wife. Anyone else in my situation would have left me. Whenever I say I need something, she brings it. She doesn't know where to get it, but she'll get it for me.”

Another participant, Mr Ikhlas, said his relationship with children is not good at all. Mr Ikhlas mentioned his relationship with children that:

“My own sons and daughters do not like me because I am disabled. When I call my daughters more than once, they get angry and say: What's the matter? Why did you call again? Why? (In a loud voice) ...Children call me 'Father' when they are in a problem, when they need money (Sad).”

Another participant, Mr Krishna, mentioned his relationship with his caring sisters. He said:

“My sisters never misbehave with me. They never regret my disability. Actually, I am not married nor have a son or daughter, and my parents are not alive. Sisters do it all for me. If they didn't take care of me, I would have died long ago.”

4.4.2 Sub-theme Two: Relationship with Relatives

Most of the participants said their relationship with their relatives is not good now. Relatives do not inquire about them now due to poverty in their old age. Mr Kafi mentioned that:

“What can I say about relatives, if you don't have money, you can't get any help from relatives. All my relatives have big jobs. They do not inquire about us now...My cousin is a doctor and has a big clinic in Moghbazar. When I had a visit to his clinic earlier, he would stand up from the chair and let me sit on it.”

One participant said that relatives always respect him as a senior in the clan. Mr Abraham said: “None of my relatives have said anything bad about me till now. Everyone still respects me because I am the elder of the clan. Everyone still inquires. Even takes my opinion as a senior while doing something.”

4.4.5 Sub-theme Three: Relationship with Colleagues

Three participants talked about their relationships with colleagues in the workplace. Two participants stated that colleagues support their work despite being older. When talking about relationships with colleagues, Mr Motiur said: “Their attitude towards me is good. They think that it is a big thing that I am earning for my family at this age despite being disabled.”

Another one participant, Mr. Amir, mentioned the neglectful attitude of colleagues:

“It has also happened that when I cut wood in the room, it is filled with dust. They do not let me open the window. They say the window would not open. If I open the window, they get angry and shout: why did you open the window? Why? (In a loud voice)”

4.5 Theme Five: Social Attitude

Each participant talks about society's attitude towards them. Participants reported both positive and negative attitudes they received from the community. Five out of the seven participants indicated that they receive negative attitudes from people in society. According to the participants' comments, two main sub-themes were identified. The related sub-theme is described as follows:

4.5.1 Sub-theme One: Bullying

Five participants mentioned that they are often oppressed by society, even in the community where they grew up old from youth. They said that people humiliate them with nasty jokes and contemptuous looks. Mr Amir mentioned that:

“The last time I went to my village home, the neighbour saw me and said "hey, the disabled is coming"... Since then, I have stopped going to the village home. Because

I hated them. I thought, how could they say this to me because I had a good relationship with them.”

4.5.2 Sub-theme Two: Supportive Attitude

Three participants indicated that people in the community respect them as elders and show a positive attitude when they need help. When talking about social attitude, Mr Motiur said: “As many people as I know in the society, everyone knows me well. When I need any help from them, they willingly come to help me.”

4.6 Theme Six: Access to Fundamental Rights for Persons with Disabilities

Bangladesh Disability Rights and Act 2013 has provided several laws to ensure fundamental rights for PWDs. All participants talked about having limited access to society's fundamental rights. Each participant stated they had limited access to fundamental rights such as healthcare services, safe residence and social participation except for the disability or old age allowance. Four main sub-themes were identified under the theme. The related sub-theme is described as follows:

4.6.1 Sub-theme One: Healthcare Facilities

Participants provided information about their access to health care facilities in old age. One participant reported being deprived of proper medical information due to the doctor's discriminatory attitude. Mr Ikhlal said: “I had to be interrupted several times when I went to the hospital for treatment. I did not even get any good medical information from a doctor. I did not see that he paid good attention to me.”

4.6.2 Sub-theme Two: Disability or Old Age Allowance

Participants talked about their access to a disability or the old age allowance. Most participants reported that they receive only disability allowance or old age allowance from

the government among their fundamental rights. Mr Krishna mentioned: “I cannot access in all social facilities. Now I only get disability allowance.”

Another participant, Mr Abraham, said: “I get old age allowance from Govt. Its amount is only five hundred takas per month. My wife also gets this allowance.”

4.6.3 Sub-theme Three: Safe Residence

Participants reported their access to safe residences. One participant said that no one wants to rent a house to him because of his disability, which deprives him of the opportunity to live safely. Mr. Ikhlas reported that:

“Some people are extremely inhumane. As I say, there are many people who don't want to rent me their house. Every few days, I have to search and change the house, which is very painful for me in my old age.”

4.6.4 Sub-theme Four: Social Participation

All participants talked about how their social participation is currently in old age. Most participants indicated their participation in religious activities and social events was restricted due to a lack of accessibility and poor physical health in old age. When they talked about their religious participation in mosque, temple and church, they identified accessibility issues as a significant problem, as well as the physical illness. Mr Mokbul said:

“I cannot go anywhere. Like I cannot go to the mosque. There is no capacity to go to the mosque. There is no road, no ramp to get up, no facility to go. I do not even go to any event in the neighbourhood... Though I think about going, I think about going to the mosque, but I cannot go with a wheel chair.”

Another participant, Mr Abraham, reported about his religious participation in the church that:

“I cannot go to church every day. When I feel sick, I sit or lie in bed all day. Because of this, I cannot always attend my religious activities. Otherwise, I have never ignored these tasks from my heart. But now I cannot do it due to illness.”

Participants also indicated the similar issue in participating in social events. When talking about social events, Mr Kafi reported accessibility issues that isolate him from his family when attending social events. He mentioned: “A few days ago, I had my niece’s wedding ceremony. My whole family participated in the ceremony, but I could not go. They all went; I stayed alone at home.”

4.7 Theme Seven: Burden of Age and Disability

Three participants indicated that older age and disability is a burden for family and productive life. They expressed themselves as a burden to their family members as well as a burden to their boss and colleagues in the workplace. One participant, Mr Kafi, mentioned that:

“Now I am very old. Now I say this to God, Almighty God, do not keep me lying at home with a sick body. Give me sudden death. Otherwise, everyone's suffering. The suffering of those who serve me and cry for me. May Allah give me death rather than suffering to others.”

Another participant mentioned being burdened at work. Mr Amir reported that:

“I have two more months to work here. I was telling my boss that if I had worked for another six months, my son's job would have been permanent by this time. My boss told me, you are old now. Now you cannot work like before. Though you are

getting a good salary, but you cannot do any work accordingly.”

4.8 Theme Eight: Resiliency

Most participants expressed that they are adapting and coping with the adversities in their lives. Participants talked about their emotional adjustment to disability. They accept their disabilities as they grow older and adapt to limitations at every stage of life. Mr Amir stated: “I do not mind if someone thinks bad about me. I will do what I like. I do not care about these things. Because if I think about these things, then I cannot live with everyone in this society.”

Another participant, Mr Ikhlas, mentioned that:

“I do not think bad things ever; that is the truth. Bad thoughts never come to my mind. I never think that I was capable like other people and that I had everything. Because if I think about these, I will have limitless pain. I can't explain how painful it will be. So, I always avoid my bad thoughts.”

CHAPTER V: DISCUSSION

The study presented the lived experience of elderly individuals with paraplegia. Seven community-living elderly paraplegic patients were interviewed in the study. The study identified eight themes which emerged from the transcript of the participant.

The study finds out the occupational role, physical and emotional health, relationships, social attitude, access to fundamental rights for PWDs, burden of age and disability and resiliency of persons with elderly paraplegia. The study indicated various occupational roles in the family and productive life, such as husband, father, brother, grandfather, employee and trader. Most participants did not mention any significant family responsibilities they have now. They withdraw their responsibilities from the family due to aged. Only three participants talked about their responsibilities to family in old age. The literature on other countries did not indicate the family role of paraplegic patients in the older age. Only three out of the seven participants have a current job and talk about their role performance in a productive life. All three participants mentioned that the progression of disability and age had changed their work role performance over time. A Canadian research mentioned the participation rate on employment of older people after injury (Jetha et al., 2014) but did not mention the work role performance of the older person in productive life.

This study reported the various physical health issues in older people, such as chronic condition and progression of SCI-related complications. Participants indicated some chronic issues they faces in old age, such as stroke, asthma, heart disease and restlessness, kidney disease, bladder stone and age-related cataract. They also reported some physical health issues such as bowel-bladder incontinence, paresthesia, hypertension, loss of

appetite, loss of strength and endurance, muscle spasms, deep vein thrombosis, autonomic dysreflexia, pressure sore and sleep disturbance as complications of SCI. The England and Canadian research also mentioned similar findings of physical health issues in the older paraplegic patient (Krassioukov et al., 2003; McGlinchey-Berroth et al., 1995). In the study's findings, All participants expressed more negative than positive emotions about their current lives. Five out of seven participants expressed positive emotions such as happiness, peace, satisfaction and blissful life in old age. On the other side, all participants expressed various negative emotions such as distress, nervousness, missing, worried, anxiety etc. The research in European countries identified the anxiety and depressive symptoms of persons with SCI (Bonanno et al., 2012; Jørgensen et al., 2017), but no published evidence explored the emotion of community-dwelling elderly person paraplegic patients.

This study explores the various relationship of older people have with family members, relatives, and colleagues in the workplace. Most participants explained that they had good relationships with their family members; the two participants revealed their ruined relationships, such as separation with wife, neglect of children and a property dispute with their brother. The research of another country also indicated that the family relationships that people with SCI are satisfied with the closeness with their family (Warren et al., 1996). However, they did not disclose the family relationship breakdown with the older person. Another finding is that most participants indicated that Relationships with relatives had broken down over time due to poverty in old age. Three participants talked about their relationships with colleagues where two out of three participants mentioned the positivity of colleagues towards them. However, the study also exposed the negativity of colleagues

towards them due to disability and old age. Even no published evidence has been found that addressed the relationships of older paraplegic patients with relatives and colleagues.

In the study, participants talked about both positive and negative attitudes they received from the community. Five participants reported bullying attitudes from society. Only three participants mentioned that society has a positive attitude towards them as an older person.

The Canadian research evaluated attitudes towards older SCI patients among nurses, where the result identified significant differences in the attitudes towards older patients (Furlan et al., 2009). However, did not explore how the society's attitude towards the older paraplegic patients after completing the rehabilitation program and re-integrating into society.

Another finding of the study is access to fundamental rights for persons with disabilities in society. According to the Person with Disabilities Rights and Protection Act in Bangladesh 2013, Around 21 special facilities have been mentioned/preserved in this law for the PWDs. Some of them are leading a life like other abled people, with legal support, heir, freedom of speech, equal access to information, accessibility, safe residence, participation in all social, financial, and state activities, education, employment, healthcare service and many others rights given by the government. In the study, most participants reported receiving only disability allowance or old age allowance from the government among their fundamental rights. They also indicated some fundamental rights to which they have limited access in old age, such as neglect from healthcare providers, lack of safe residence and restricted social participation due to lack of accessibility and poor health condition. The research from Switzerland mentioned the social support of spinal cord injury patients with higher psychological distress and poorer mental health, vitality, energy and quality of life, lower self-efficacy and relationship satisfaction, lived

more frequently alone, and were more frequently single in the society (Carrard et al., 2021). Another research from Sweden indicated similar findings about accessibility that housing adaptations and environmental barriers were common, and accessibility problems were associated with less participation (Norin et al., 2017).

In the study, three participants expressed their old age and disability as burdens for their families and productive lives. In China, A retrospective cohort study findings the incidence and burden of SCI have increased over the last 30 years in males and persons with elderly were affected more (Weizhong et al., 2022). But they did not explore the burden of life of the elderly persons with spinal cord injury. Another finding of the study is resiliency in old age. Most of the participants expressed that they accept their disabilities as they grow older and adapt themselves to limitations at every stage of life. But there is limited published evidence about resilience in the elderly paraplegic patient.

The overall findings of this study help us to understand the life of the elderly persons with paraplegia from different points of view, such as their occupational role in family and productive life, current different health issues, various relationships, Society attitudes, needs and rights from society, burden of life and resiliency with time. The study's findings are essential for the implication of new practices in the rehabilitation sector. By implementing new practices, the elderly paraplegic patients can benefit from the rehabilitation phase as well as the community.

CHAPTER VI: CONCLUSION

6.1 Strengths and Limitations

6.1.1 Strengths

- ▶ The unique feature of this study is that, in addition to fulfilling the aims and objectives of the study, it also explored some study-related additional information about the lives of the elderly persons with paraplegia.
- ▶ Face to face in-depth interview was conducted in real-life contexts.
- ▶ Field notes and reflective diaries were used to keep track of observations that maintained appropriateness and adequacy.
- ▶ Field test was conducted to avoid ambiguity and refine the questions of interview guide.
- ▶ Member checking was performed with six participants to maintain the validation and accuracy of data.
- ▶ The knowledge gained from the study might be helpful for occupational therapy practice in the geriatric care of paraplegic patients.
- ▶ This study will help further research on this phenomenon through which this area will be explored in future.
- ▶ Consolidated criteria for reporting qualitative research (COREQ) checklist was used for reporting the vital aspect of the study.

6.1.2 Limitations

- ▶ This study was conducted on elderly male paraplegic patients. Female paraplegic patients aged 60 years and above could not reach because of the early death and incorrect contact numbers.
- ▶ Unable to conduct member checking with one participant due to his sudden death
- ▶ All participants were over 60 years of age for which some participants slurred some words during the interview
- ▶ Study setting was only Savar Upazila because of the short study period
- ▶ Data were only collected from paraplegic SCI participants in this study, so finding cannot be generalized to those with other forms of SCI.

6.2 Practice Implication

This thesis can be a part of the healthcare sector for various healthcare providers. Doctors, nurses, psychologists, counsellors, and therapists can play an essential role in the care of elderly paraplegic patient by gaining knowledge from the thesis. These will help to ensure the client-centred practice for the elderly persons with paraplegia by an interdisciplinary rehabilitation team.

As this is a new area, this thesis can develop theoretical knowledge of occupational therapy practice in the geriatric care of paraplegic patients in Bangladesh. Since an occupational therapist works with a client's multidimensional needs. This thesis can help the occupational therapist to emphasise the different aspects of the elderly paraplegic patient, such as the individual's physical, mental, social and family problems. It may therefore be able to expand occupational therapy services to hospital-based and community-based practice.

6.3 Recommendation for Further Research

- ▶ Further research should be conducted on the lived experience of the elderly women with paraplegia
- ▶ Further research is recommended to investigate the prevalence of mental health issues of the elderly individuals with paraplegia.
- ▶ Further research should be conducted on the lived experience of the elderly individuals with tetraplegia

6.4 Conclusion

The elderly persons with paraplegia experience various issues in their family and community life. They had different experiences physically, psychologically and socially. Specialised geriatric care service is essential in rehabilitation centres and community levels for ensuring their quality of life. Along with geriatric care services, we need to create awareness to increase access of people with disabilities to fundamental rights in our community. On the other side, this study explored a new area of spinal cord injury, so we need to conduct more research on the area of elderly persons with spinal cord injury. If we conduct further studies in this area, then we can explore more information about the elderly population with spinal cord injury that can help to improve the evidence-based practice in our rehabilitation sector.

CHAPTER VII: REFERENCES

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APPENDICES

Appendix A1: Ethical Approval Form



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

Ref: Date:

CRP/BHPI/IRB/09/22/642 28th September, 2022

Fariha Hossain Emu
 4th Year B.Sc. In Occupational Therapy
 Session: 2017-2018 Student ID: 122170282
 BHPI, CRP, Savar, Dhaka-1343, Bangladesh

Subject: Approval of the thesis proposal “Lived experience of elderly individuals with paraplegia” by ethics committee.

Dear Fariha Hossain Emu,
 Congratulations.
 The Institutional Review Board (IRB) of BHPI has reviewed and discussed your application to conduct the above-mentioned dissertation, with yourself, Md. Julker Nayan as thesis supervisor. The Following documents have been reviewed and approved:

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

The purpose of the study is to explore the lived experience of elderly individuals with paraplegia. The study involves use of a self-developed interview guide to explore the lived experience of elderly individuals with paraplegia that may take 60 to 90 minutes to answer the questionnaire and there is no likelihood of any harm to the participants. The members of the Ethics committee have approved the study to be conducted in the presented form at the meeting held at 8.30 AM on 27th August, 2022, at BHPI (32nd IRB Meeting).

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

নিআরপি-চাপাইন, সাভার, ঢাকা-১৩৪৩, বাংলাদেশ। ফোন: +৮৮ ০২ ২২৪৪৪৫৪৬৪-৫, +৮৮ ০২ ২২৪৪৪১৪০৪, মোবাইল: +৮৮ ০১৭৩০ ০৫৯৬৪৭
 CRP-Chapain, Savar, Dhaka-1343, Bangladesh. Tel: +88 02 224445464-5, +88 02 224441404, Mobile: +88 01730059647
 E-mail : principal-bhpi@crp-bangladesh.org, Web: bhpi.edu.bd

Appendix A1: Approval for Conduct Research Project

Date: 11 October 2022
 To
 The Head
 Dept. Of Occupational Therapy
 Bangladesh Health Professions Institute

Subject: Prayer for seeking to conduct the research project

Sir,

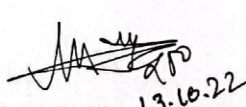
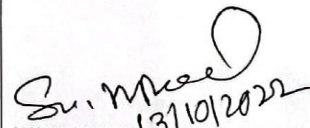
With due respect I am seeking permission to conduct the research project as a part of my 4th year course module. My research title is **“Lived experience of elderly individuals with paraplegia”**. The aim of the study is to explore the lived experience of elderly individuals with paraplegia. Now I am looking for your kind approval to start my research project and I would like to assure that anything of my project will not harmful for the participants.

So, I therefore pray and hope that your honor would be kind enough to grant me the permission of conducting the research and will help me to conduct a successful study as a part of my course.

Your faithfully,

Fariha

.....
 Fariha Hossain Emu
 4th year B.Sc in Occupational Therapy
 Session: 2017-2018
 Bangladesh Health Professions Institute
 CRP, Savar, Dhaka-1343

Signature and comments of the Supervisor	Signature and comments of the Head of the Dept.
 13.10.22 Md. Julker Nayan Associate Professor & Head Department of Occupational Therapy Centre for the Rehabilitation of the Paralysed (CRP) Savar, Dhaka-1343, Bangladesh.	 13/10/2022 Sk. Moniruzzaman Associate Professor & Head Department of Occupational Therapy Bangladesh Health Professions Institute Centre for the Rehabilitation of the Paralysed (CRP) Savar, Dhaka-1343, Bangladesh.

Appendix A2: Data collection approval from CBR Department

গণিত বিষয়ক প্রার্থনা
CRP (সাবার, ঢাকা)

Date: 11 October, 2022

To
Head of Rehabilitation Division
Centre for the Rehabilitation of the Paralysed
CRP-Chapain, Savar, Dhaka-1343

Subject: Prayer for permission to collect data for the research project

Sir,

With due respect to state that, I am Fariha Hossain Emu, 4th year student of B.Sc in Occupational Therapy department of 2017-2018 session, at Bangladesh Health Professions Institute (BHPI), the academic institute of Centre for the Rehabilitation of the Paralysed (CRP). As I am student of 4th year, I have to do a research for my academic purpose. The area of my research is spinal cord injury and my research title is "Lived experience of elderly individuals with paraplegia". As it is phenomenological qualitative research, I would like to take the interview of paraplegic male people who have completed rehabilitation program from CRP. So that's why I needed the address and additional information of patients who have got treatment from CRP.

So I therefore pray and hope that you would be kind enough to give me permission to take the address and additional information of male paraplegic people who are discharged after completing full rehabilitation from CRP and help me to complete the project successfully.

Sincerely,

Fariha

.....
Fariha Hossain Emu
4th year B.Sc in Occupational Therapy
Session: 2017-2018
Bangladesh Health Professions Institute
CRP, Savar, Dhaka-1343

Permission from head of the Department of Occupational Therapy,

Sk. Moniruzzaman

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

Md. Julker Nayan

.....
Md. Julker Nayan
Associate Professor & Head
Department of Occupational Therapy
Centre for the Rehabilitation of the
Paralysed (CRP)
Savar, Dhaka-1343, Bangladesh.

Appendix A2: Data collection approval from SCIDAB Organisation

Date: 3 November, 2022

To
General Secretary of Spinal Cord Injuries' Development Association Bangladesh
(SCIDAB)
Centre for the Rehabilitation of the Paralysed
CRP-Chapain, Savar, Dhaka-1343

Subject: Prayer for permission to collect data for the research project

Sir,

With due respect to state that, I am Fariha Hossain Emu, 4th year student of B.Sc in Occupational Therapy department of 2017-2018 session, at Bangladesh Health Professions Institute (BHPI), the academic institute of Centre for the Rehabilitation of the Paralysed (CRP). As I am student of 4th year, I have to do a research for my academic purpose. The area of my research is spinal cord injury and my research title is "Lived experience of elderly individuals with paraplegia". As it is phenomenological qualitative research, I would like to take the interview of paraplegic male people who have completed rehabilitation program from CRP. Many spinal cord injury patients who have completed rehabilitation programs from CRP and are living in the community are now members of your organization. So that's why I needed the address and additional information of SCI patient who are now members of your organization for my research project.

So I therefore pray and hope that you would be kind enough to give me permission to take the address and additional information of SCI people who are discharged after completing full rehabilitation from CRP and help me to complete the project successfully.

Sincerely,

Fariha

.....
Fariha Hossain Emu
4th year B.Sc in Occupational Therapy
Session: 2017-2018
Bangladesh Health Professions Institute
CRP, Savar, Dhaka-1343

Permission from head of the Department of Occupational Therapy,

Sk. Moniruzzaman
.....
Sk. Moniruzzaman 25/11/2022
Associate Professor & Head
Department of Occupational Therapy
Bangladesh Health Professions Institute
Centre for the Rehabilitation of the Paralysed (CRP)
Savar, Dhaka-1343, Bangladesh.

*Yes,
I am agreed on the topic.
Go ahead for collection data
from elderly people with
Fariha*

Appendix B1: Information Sheet, Consent Form and Withdrawal Form (English)**Participant Information Sheet****Project Title: “Lived experience of elderly individuals with paraplegia”****Student Investigator: Fariha Hossain Emu**4th year Occupational Therapy Student

Bangladesh Health Professions Institute (BHPI)

Phone number:01673560608

Email:farihaemu07@gmail.com

Research Supervisor: Julker Nayan

Associate Professor

Department of Occupational Therapy,

BHPI, CPR, Savar, and Dhaka-1343.

Email:julkernayan@gmail.com

What does the research involve?

Please read this information sheet before deciding to participate in this research. If you would like to further ask any information regarding this research, please contact the mentioned phone number or email address.

► You are invited to take a part of face-to-face in-depth semi-structured interview by student investigator at your home. The interview will be at a pre-scheduled time which is approximately 60-90 minutes.

► You will be asked to share your experience with spinal cord injury at this old age. I expect from you that you share about your physical experience, psychological experience, social experience and family relationship in details.

► You will be asked some basic question like age, gender, type of SCI, date of incident and date of discharge from CRP. With your kind permission, we will also collect your medical reports from CRP database.

Why you are chosen for this research?

You have been invited for participate in the research because of your age is 60 years or above and have at least two years lived experience with spinal cord injury in the community.

Source of funding

The Institute does not contribute any funding for this project. The student researcher will bear all financial expenses.

Consenting to participate in the project and withdrawing from the research

If you are interested and agree to participate in this project than,you will need to signature/tip signature on written consent form that will deliver student researcher before the interview. Moreover if you consent to participate,you have the opportunity to withdraw your consent and participation from the research.The condition is to withdraw your consent and all interview information within one month from the date of interview. There will be no negative consequence if you choose to withdraw your consent or participation from this study.

Possible benefits and risks to participants

I regret that you may not receive any direct or financial benefit for participating in this study. However, the information that we gain from your interview can help develop occupational therapy services for the elderly spinal cord injury population.Through which elderly people with spinal cord injury in Bangladesh will benefit from this service.

There is no possibility of any risk or harm to the participant during and after the research.

Confidentiality

All information you provide must be kept confidential. It can be accessible only by the researcher due to the purpose of conducting the research. Your name will not be mentioned in published documents. In the research, an identification code will be used to replace your name. No one can access original transcripts that have your name except the student researcher and supervisor.

Storage of Data

All gathered data (recording, field notes and transcripts) will be stored in a password-protected computer and personal Google Drive, so that no one can access the storage of data except the student researcher for conducting this study. All hard copies of data will be destroyed.

Result

Results from the study will be documented in the student theses as a part of the Occupational Therapy department at Bangladesh Health Profession Institute (BHPI). If you are interested to know about the summary of project results, then contact with the student investigator or supervisor at the above contact details.

Complaints

Should you have any concern or complaints about the conduct of the project, you are welcome to contact the Institutional Ethics Committee of Bangladesh Health Profession Institute.

Bangladesh Health Profession Institute (BHPI)

CRP-Chapain, Savar Union 1343, Bangladesh

Thank you,

Fariha Hossain Emu

4th year Occupational Therapy Student

Consent Form

Research Title: “Lived experience of elderly individuals with paraplegia”

Student Investigator: Fariha Hossain Emu

I have been asked to be a participate in a research project mentioned above. I have read and understood the Participant information sheet and I hereby consent to participate in this study.

I consent of the following things	Yes	No
Participating on semi-structured in-depth interview lasting approximately 60-90 minutes	<input type="checkbox"/>	<input type="checkbox"/>
Audio recording during the interview	<input type="checkbox"/>	<input type="checkbox"/>

Name of Participant:.....

Signature/tip signature of participant:.....

Signature of student investigator:.....

Date:.....

Withdrawal Form

Research Title: “Lived experience of elderly individuals with paraplegia”

Student Investigator: Fariha Hossain Emu

I.....(Participant Name) would like to withdraw my consent and participation from the research study referenced above. Data that collect from me must not be used in this research as described in participant information sheet. I withdraw my consent within 1 month as the condition was stated in information sheet. I hope you remove my information which I provided in the interview for your research project.

Name of participant:.....

Signature/tip signature of participant:.....

Date:.....

Appendix B2: Information Sheet, Consent Form and Withdrawal Form (Bangla)

অংশগ্রহণকারীর তথ্যপত্র

গবেষনার নামঃ বয়স্ক প্যারাপ্লেজিয়া ব্যক্তিদের জীবন যাপনের অভিজ্ঞতা

গবেষক ছাত্রীঃ ফারিহা হোসেন ইমু

অকুপেশনাল থেরাপি ৪র্থ বর্ষের ছাত্রী

বাংলাদেশ হেলথ প্রফেশনস ইনস্টিটিউট (বিএইচপিআই)

ফোন নাম্বারঃ ০১৬৭৩৫৬০৬০৮

Email: farihaemu07@gmail.com

গবেষণার তত্ত্বাবধাওকঃ জুলকার নায়েন

সহযোগী অধ্যাপক

অকুপেশনাল থেরাপি বিভাগ,

বিএইচপিআই, সি আর পি, সাতার এবং ঢাকা-১৩৪৩।

Email: julkernayan@gmail.com

গবেষণা কি জড়িত?

এই গবেষণায় অংশগ্রহণ করার সিদ্ধান্ত নেওয়ার আগে অনুগ্রহ করে এই অংশগ্রহণকারীর তথ্যপত্রটি পড়ুন। আপনি যদি এই গবেষণার বিষয়ে আরও কোন তথ্য জিজ্ঞাসা করতে চান তবে অনুগ্রহ করে উল্লিখিত ফোন নম্বর বা ইমেলে যোগাযোগ করুন।

► আপনার বাড়িতে ছাত্রী গবেষক দ্বারা আধা-কাঠামোগত মুখোমুখি গভীর সাক্ষাৎকারে অংশগ্রহণ করার জন্য আপনাকে অনুরোধ করা হচ্ছে। সাক্ষাৎকারটি একটি পূর্বনির্ধারিত সময়ে হবে যা প্রায় ৬০-৯০ মিনিট।

► আপনাকে এই বৃদ্ধ বয়সে মেরুদণ্ডের আঘাতের সাথে আপনার অভিজ্ঞতা শেয়ার করতে বলা হবে। আমি আপনার কাছ থেকে আশা করি যে আপনি আপনার শারীরিক অভিজ্ঞতা, মনস্তাত্ত্বিক অভিজ্ঞতা, সামাজিক অভিজ্ঞতা এবং পারিবারিক সম্পর্ক বিষয়ে বিস্তারিতভাবে শেয়ার করবেন।

► এছাড়াও আপনাকে বয়স, লিঙ্গ, বর্তমান চাকরি, এসসিআই-এর ধরন, ঘটনার তারিখ এবং সিআরপি থেকে ছাড়ার তারিখের মতো কিছু মৌলিক প্রশ্নও জিজ্ঞাসা করা হবে।

কেন আপনি এই গবেষণার জন্য নির্বাচিত?

আপনাকে গবেষণায় অংশগ্রহণের জন্য অনুরোধ করা হচ্ছে কারণ আপনার বয়স ৬০ বছর বা বেশি এবং মেরুদণ্ডের আঘাতের সাথে সমাজে কমপক্ষে দুই বছর বসবাসের অভিজ্ঞতা রয়েছে।

তহবিলের উৎস

ইনস্টিটিউট এই প্রকল্পের জন্য কোন অর্থায়ন অবদান রাখে না। গবেষক ছাত্রী সকল আর্থিক ব্যয় বহন করবেন।

প্রকল্পে অংশগ্রহণের জন্য সম্মতি এবং গবেষণা থেকে প্রত্যাহার

আপনি যদি আগ্রহী হন এবং এই গবেষণায় অংশগ্রহণ করতে সম্মত হন, তাহলে আপনাকে লিখিত সম্মতি ফর্মে স্বাক্ষর/টিপ স্বাক্ষর করতে হবে যা সাক্ষাতকারের পূর্বে ছাত্রী গবেষক প্রদান করবে। তাছাড়া আপনি যদি অংশগ্রহণের জন্য সম্মত হন, তাহলে গবেষণা থেকে আপনার সম্মতি এবং অংশগ্রহণ প্রত্যাহার করার সুযোগ রয়েছে। শর্ত হল সাক্ষাতকারের তারিখ থেকে এক মাসের মধ্যে আপনার সম্মতি এবং সমস্ত সাক্ষাতকারের তথ্য প্রত্যাহার করতে হবে। আপনি যদি এই গবেষণা থেকে আপনার সম্মতি বা অংশগ্রহণ প্রত্যাহার করতে চান তবে তার কোন নেতিবাচক পরিণতি হবে না।

অংশগ্রহণকারীদের সম্ভাব্য সুবিধা এবং ঝুঁকি

আমি দুঃখিত যে আপনি এই গবেষণায় অংশগ্রহণের জন্য কোনো আর্থিক বা প্রত্যক্ষ সুবিধা নাও পেতে পারেন। যাইহোক, আপনার সাক্ষাতকার থেকে আমরা যে তথ্য লাভ করবো তা বয়স্ক মেরুদণ্ডের আঘাতজনিত জনসংখ্যার জন্য অকুপেশনাল থেরাপি পরিষেবা বিকাশে সহায়তা করতে পারে। যার মাধ্যমে বাংলাদেশের মেরুদণ্ডের আঘাতে আক্রান্ত বয়স্ক ব্যক্তির এই সেবার সুবিধা পাবেন।

গবেষণা চলাকালীন এবং পরে অংশগ্রহণকারীর কোন ঝুঁকি বা ক্ষতির সম্ভাবনা নেই।

গোপনীয়তা

আপনার দেওয়া সমস্ত তথ্য অবশ্যই গোপন রাখা হবে। গবেষণা পরিচালনার উদ্দেশ্যের কারণে এটি শুধুমাত্র গবেষক দ্বারা প্রবেশযোগ্য হতে পারে। প্রকাশিত নথিতে আপনার নাম

উল্লেখ করা হবে না। গবেষণায়, আপনার নাম প্রতিস্থাপন করে একটি শনাক্তকরণ কোড ব্যবহার করা হবে। ছাত্রী গবেষক বা গবেষণার তত্ত্বাবধায়ক ছাড়া আপনার নাম আছে এমন মূল প্রতিলিপিতে কেউ প্রবেশ করতে পারবে না।

তথ্য ভাণ্ডার

সমস্ত সংগৃহীত তথ্য(রেকর্ডিং, ফিল্ড নোট এবং ট্রান্সক্রিপ্ট) একটি পাসওয়ার্ড সুরক্ষিত কম্পিউটার এবং ব্যক্তিগত গুগল ড্রাইভে সংরক্ষণ করা হবে, যাতে এই গবেষণা পরিচালনার জন্য ছাত্রী গবেষক ব্যতীত কেউ তথ্য ভাণ্ডারে প্রবেশ করতে না পারে। সমস্ত তথ্যের হার্ড কপি ধ্বংস করা হবে।

ফলাফল

বাংলাদেশ হেলথ প্রফেশনাল ইনস্টিটিউট (বিএইচপিআই) এর অকুপেশনাল থেরাপি বিভাগের অংশ হিসাবে গবেষণার ফলাফল ছাত্র থিসিসে নথিভুক্ত করা হবে। আপনি যদি প্রকল্পের ফলাফলের সারমর্ম সম্পর্কে জানতে আগ্রহী হন তবে উপরে বিস্তারিত উল্লেখিত যোগাযোগের ঠিকানায়ে ছাত্রী গবেষক বা গবেষণার তত্ত্বাবধায়কের সাথে যোগাযোগ করুন।

অভিযোগ

গবেষণা পরিচালনার বিষয়ে আপনার কোন উদ্বেগ বা অভিযোগ থাকলে, বাংলাদেশ হেলথ প্রফেশনস ইনস্টিটিউটের ইনস্টিটিউশনাল এথিক্স কমিটির সাথে যোগাযোগ করার জন্য আপনাকে স্বাগতম।

বাংলাদেশ হেলথ প্রফেশনস ইনস্টিটিউট (বিএইচপিআই)

সিআরপি-চাঁপাইন, সাভার ইউনিয়ন ১৩৪৩, বাংলাদেশ

ধন্যবাদ,

ফারিহা হোসেন ইমু

অকুপেশনাল থেরাপি ৪র্থ বর্ষের ছাত্রী

সম্মতিপত্র

গবেষনার নাম: বয়স্ক প্যারাপ্লেজিয়া ব্যক্তিদের জীবন যাপনের অভিজ্ঞতা

গবেষক ছাত্রী: ফারিহা হোসেন ইমু

আমাকে উপরে উল্লিখিত একটি গবেষণা প্রকল্পে অংশগ্রহণ করার জন্য বলা হয়েছে আমি অংশগ্রহণকারীর তথ্যপত্রটি পড়েছি এবং বুঝেছি এবং আমি এতদ্বারা এই গবেষণায় অংশগ্রহণ করতে সম্মতি দিচ্ছি।

আমি নিম্নলিখিত বিষয়গুলিতে সম্মতি জানাচ্ছি	হ্যাঁ	না
প্রায় ৬০-৯০ মিনিট স্থায়ী অর্ধ-গঠিত গভীর সাক্ষাৎকারে অংশগ্রহণ করা	■	■
সাক্ষাৎকারের সময় অডিও রেকর্ডিং	■	■

অংশগ্রহণকারীর নাম:.....

অংশগ্রহণকারীর স্বাক্ষর/টিপ স্বাক্ষর:

গবেষক ছাত্রীর স্বাক্ষর:.....

তারিখ:.....

প্রত্যাহারপত্র

গবেষনার নামঃ বয়স্ক প্যারাপ্লেজিয়া ব্যক্তিদের জীবন যাপনের অভিজ্ঞতা

গবেষক ছাত্রীঃ ফারিহা হোসেন ইমু

আমি(অংশগ্রহণকারীর নাম) উপরে উল্লিখিত গবেষণা থেকে আমার সম্মতি এবং অংশগ্রহণ প্রত্যাহার করতে চাই। আমার কাছ থেকে সংগ্রহ করা ডেটা অংশগ্রহণকারীর তথ্যপত্রে বর্ণিত তথ্য অনুযায়ী এই গবেষণায় ব্যবহার করা উচিত নয়। আমি এক মাসের মধ্যে আমার সম্মতি প্রত্যাহার করছি কারণ শর্তটি অংশগ্রহণকারীর তথ্যপত্রে বলা হয়েছে। আমি আশা করি আপনি আমার তথ্য মুছে ফেলেবেন যা আমি আপনার গবেষণা প্রকল্পের জন্য সাক্ষাত্কারে প্রদান করেছি।

অংশগ্রহণকারীর নাম:.....

অংশগ্রহণকারীর স্বাক্ষর/টিপ স্বাক্ষর:

তারিখ:.....

Appendix C1: Modified Interview Guide (English)

Interview Guide

Date of interview:

Socio-Demographic Information:

- Age at injury
- Age at interview

SCI Information

- Date of incident
- History of incident
- Diagnosis
- Mobility aid
- Pre-injury job
- Current job (if any)

Introductory Question

- ▶ How are you with your family and community now after getting treatment from CRP?

Aim	Objective	Question
Lived experience of elderly individuals with paraplegia	to explore physical experience of elderly individuals with paraplegia	<ul style="list-style-type: none"> ▶ What physical changes are you experiencing at this age for a spinal cord injury? ▶ Explain which physical problems become more serious in old age due to spinal cord injury? ▶ Describe how these physical issues are causing problems in your daily life?

		<ul style="list-style-type: none"> ▶ Please give me any example of your physical issue that is causing problems in your life right now? ▶ How are you coping and adapting to these problems in everyday life?
	<p>to explore psychological experience of elderly individuals with paraplegia</p>	<ul style="list-style-type: none"> ▶ How do you feel about yourself with spinal cord injury in old age? ▶ Explain what things you like to think about? ▶ Please give me examples that you like to think about? ▶ Explain what things makes you feel bad when you think about them? ▶ Please give me examples that make you feel bad when you think about it?
	<p>to explore social experience of elderly individuals with paraplegia</p>	<ul style="list-style-type: none"> ▶ Can you tell me how you feel about your peers, neighbors and people in your community? ▶ Describe how your relationship with your peers, neighbors and community people at this age? ▶ Explain how their attitude towards on you? ▶ Tell me about your access to social facilities with spinal cord injury? ▶ Explain your involvement in social activities with spinal cord injury?

	<p>to explore family relationship of elderly individuals with paraplegia</p>	<ul style="list-style-type: none"> ▶ Can you tell me about your family member? ▶ Describe how about your relationship with your family members in old age? ▶ How does your family feel about you for changes due to spinal cord injury? As well as your relatives? ▶ What are your family members taking care of you about? ▶ Can you tell me what are your roles and responsibilities towards the family now? ▶ How are you fulfilling your role and responsibilities towards your family to maintain an effective relationship with family?
		<p>Additional question if any job,</p> <ul style="list-style-type: none"> ▶ What are your responsibilities at work? ▶ How does disability and old age influencing in your job performance? ▶ Describe what problems you face in your workplace? ▶ Explain how the attitude of people towards on you in the workplace? ▶ Can you tell me about your accessibility at workplace?

Closing Question

- ▶ Is there anything else you would like to add about your experience with spinal cord injury?

Appendix C1: Modified Interview Guide (Bangla)

ইন্টারভিউ গাইড

সাক্ষাৎকারের তারিখ:

সামাজিক-জনসংখ্যাগত তথ্য

- বয়স (আঘাতের সময়)
- বয়স (সাক্ষাৎকারের সময়)

মেরুরজ্জুতে আঘাতজনিত তথ্য

- ঘটনার তারিখ
- ঘটনার ইতিহাস
- আঘাতের ধরন
- আঘাতের পূর্বে পেশা
- বর্তমান পেশা (যদি থাকে)

সূচনামূলক প্রশ্ন

- ▶ সি আর পি থেকে চিকিৎসা নিয়ে আসার পর এখন আপনি আপনার পরিবার এবং সমাজের সাথে কেমন আছেন?

লক্ষ্য	উদ্দেশ্য	প্রশ্ন
বয়স্ক প্যারাপ্লেজিয়া ব্যক্তিদের জীবন যাপনের অভিজ্ঞতা	বয়স্ক প্যারাপ্লেজিয়া ব্যক্তিদের শারীরিক অভিজ্ঞতা অন্বেষণ করা	<ul style="list-style-type: none"> ▶ মেরুরজ্জুতে আঘাতের জন্য এই বয়সে আপনি কোন কোন শারীরিক পরিবর্তনগুলো অনুভব করছেন? ▶ মেরুরজ্জুতে আঘাতের কারণে বৃদ্ধ বয়সে কোন শারীরিক সমস্যাগুলি আরও গুরুতর হচ্ছে তা ব্যাখ্যা করুন? ▶ এই শারীরিক সমস্যাগুলি আপনার দৈনন্দিন জীবনে কীভাবে সমস্যা সৃষ্টি করছে তা বর্ণনা করুন?

		<ul style="list-style-type: none"> ▶ দয়া করে আমাকে আপনার শারীরিক সমস্যার কোন উদাহরণ দিন যা এই মুহূর্তে আপনার জীবনে সমস্যা সৃষ্টি করেছে? ▶ ব্যাখ্যা করুন কিভাবে আপনি দৈনন্দিন জীবনে এই সমস্যাগুলি মোকাবেলা করছেন এবং মানিয়ে নিচ্ছেন?
	<p>বয়স্ক প্যারাপ্লেজিয়া ব্যক্তিদের মনস্তাত্ত্বিক অভিজ্ঞতা অন্বেষণ করা</p>	<ul style="list-style-type: none"> ▶ বৃদ্ধ বয়সে মেরুরজ্জুতে আঘাত নিয়ে আপনার নিজের প্রতি কি অনুভূতি হয় ? ▶ ব্যাখ্যা করুন কোন জিনিসগুলো চিন্তা করলে আপনার ভালো লাগে? ▶ দয়া করে আমাকে উদাহরণ দিন যে বিষয়ে চিন্তা করলে আপনার ভালো লাগে? ▶ ব্যাখ্যা করুন কোন জিনিসগুলো চিন্তা করলে আপনার খারাপ লাগে? ▶ দয়া করে আমাকে উদাহরণ দিন যে বিষয়ে চিন্তা করলে আপনার খারাপ লাগে?
	<p>বয়স্ক প্যারাপ্লেজিয়া ব্যক্তিদের সামাজিক অভিজ্ঞতা অন্বেষণ করা</p>	<ul style="list-style-type: none"> ▶ আপনি কি আমাকে বলতে পারেন আপনার সমবয়সী প্রতিবেশি এবং সমাজের লোকদের সম্পর্কে আপনি কেমন অনুভব করেন? ▶ এই বয়সে আপনার সমবয়সী, প্রতিবেশি এবং সমাজের মানুষের সাথে আপনার সম্পর্ক কেমন তা বর্ণনা করুন? ▶ আপনার প্রতি তাদের মনোভাব কেমন তা ব্যাখ্যা করুন? ▶ মেরুরজ্জুতে আঘাত নিয়ে সামাজিক সুবিধাগুলোতে আপনার প্রবেশগম্যতা সম্পর্কে আমাকে বলুন? ▶ মেরুরজ্জুতে আঘাত নিয়ে আপনার সামাজিক কর্মকাণ্ডে অংশগ্রহণ সম্পর্কে ব্যাখ্যা করুন?

	<p>বয়স্ক প্যারাপ্লেজিয়া ব্যক্তিদের পারিবারিক সম্পর্ক অন্বেষণ করা।</p>	<ul style="list-style-type: none"> ▶ আপনি কি আমাকে আপনার পরিবারের সদস্যদের সম্পর্কে বলতে পারেন? ▶ বৃদ্ধ বয়সে আপনার পরিবারের সদস্যদের সাথে আপনার সম্পর্ক কেমন তা বর্ণনা করুন? ▶ মেরুদণ্ডজুতে আঘাতের কারণে পরিবর্তনের জন্য আপনার পরিবার আপনার সম্পর্কে কেমন অনুভব করে? পাশাপাশি আপনার আত্মীয়-স্বজনরা? ▶ আপনার পরিবারের সদস্যরা আপনার কী কী বিষয়ে যত্ন নিচ্ছেন? ▶ আপনি কি আমাকে বলবেন এখন পরিবারের প্রতি আপনার ভূমিকা এবং দায়িত্বগুলো কি কি? ▶ পরিবারের সাথে ভালো / কার্যকরী সম্পর্ক বজায় রাখতে আপনি কীভাবে আপনার পরিবারের প্রতি আপনার ভূমিকা এবং দায়িত্ব পালন করছেন?
		<p>অতিরিক্ত প্রশ্ন যদি কোন চাকরি থাকে,</p> <ul style="list-style-type: none"> ▶ কর্মক্ষেত্রে আপনার দায়িত্বগুলো কি কি? ▶ প্রতিবন্ধকতা এবং বার্ধক্য কীভাবে আপনার কাজের কর্মক্ষমতাকে প্রভাবিত করছে? ▶ আপনি আপনার কর্মক্ষেত্রে কোন কোন সমস্যার সম্মুখীন হচ্ছেন তা বর্ণনা করুন? ▶ কর্মক্ষেত্রে আপনার প্রতি মানুষের মনোভাব কেমন তা ব্যাখ্যা করুন? ▶ আপনি কি আমাকে কর্মক্ষেত্রে আপনার প্রবেশগম্যতা সম্পর্কে বলতে পারেন?

সমাপ্তি মূলক প্রশ্ন

- ▶ মেরুদণ্ডের আঘাতের সাথে আপনার অভিজ্ঞতা সম্পর্কে আপনি কি অন্য কিছু যোগ করতে চান?

Appendix C2: Initial Interview Guide (English)

Interview Guide

Date of interview:

Socio-Demographic Information:

- Age at injury
- Age at interview

SCI Information

- Diagnosis
- Date of incident
- Pre-injury job
- Current job (If any)

Introductory Question

- ▶ How are you with your family and community now after getting treatment from CRP?

Aim	Objective	Question
Lived experience of elderly individuals with paraplegia	to explore physical experience of elderly individuals with paraplegia	<ul style="list-style-type: none"> ▶ What physical changes are you experiencing at this age for a spinal cord injury? ▶ Explain which physical problems become more serious in old age due to spinal cord injury? ▶ Describe how these physical issues are causing problems in your life? ▶ Please give me any example of your physical issue that is causing problems in your life right now?

		<ul style="list-style-type: none"> ▶ How are you coping and adapting to these problems in everyday life?
	to explore psychological experience of elderly individuals with paraplegia	<ul style="list-style-type: none"> ▶ How do you feel about yourself with spinal cord injury in old age? ▶ Explain what things you like to think about? ▶ Please give me examples that you like to think about? ▶ Explain what things makes you feel bad when you think about them? ▶ Please give me examples that make you feel bad when you think about it?
	to explore social experience of elderly individuals with paraplegia	<ul style="list-style-type: none"> ▶ Can you tell me how you feel about your peers and people in your community? ▶ Describe your relationship with your peers and community at this age? ▶ Explain how their attitude towards on you? ▶ Tell me about your access to social facilities with spinal cord injury? ▶ Explain your involvement in social activities with spinal cord injury?
	to explore family relationship of elderly individuals with paraplegia	<ul style="list-style-type: none"> ▶ Can you tell me about your family member?

		<p>▶ Describe how about your relationship with your family members in old age?</p> <p>▶ How does your family feel about you for changes due to spinal cord injury?</p> <p>▶ What are your family members taking care of you in this old age?</p> <p>▶ Can you tell me what are your roles and responsibilities towards the family now?</p> <p>▶ How are you fulfilling your role and responsibilities towards your family to maintain an effective relationship with family?</p>
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Closing Question

- ▶ Is there anything else you would like to add about your experience with spinal cord injury?

Appendix C2: Initial Interview Guide (Bangla)

ইন্টারভিউ গাইড

সাক্ষাৎকারের তারিখ:

সামাজিক-জনসংখ্যাগত তথ্য

- বয়স (আঘাতের সময়)
- বয়স (সাক্ষাৎকারের সময়)

মেরুদণ্ডে আঘাতজনিত তথ্য

- আঘাতের ধরন
- ঘটনার তারিখ
- আঘাতের পূর্বে পেশা
- বর্তমান পেশা (যদি থাকে)

সূচনামূলক প্রশ্ন

- ▶ সি আর পি থেকে চিকিৎসা নিয়ে আসার পর এখন আপনি আপনার পরিবার এবং সম্প্রদায়ের সাথে কেমন আছেন?

লক্ষ্য	উদ্দেশ্য	প্রশ্ন
বয়স্ক প্যারাপ্লেজিয়া ব্যক্তিদের জীবন যাপনের অভিজ্ঞতা	বয়স্ক প্যারাপ্লেজিয়া ব্যক্তিদের শারীরিক অভিজ্ঞতা অন্বেষণ করা	<ul style="list-style-type: none"> ▶ মেরুদণ্ডের আঘাতের জন্য এই বয়সে আপনি কোন কোন শারীরিক পরিবর্তনগুলো অনুভব করছেন? ▶ মেরুদণ্ডে আঘাতের কারণে বৃদ্ধ বয়সে কোন শারীরিক সমস্যাগুলি আরও গুরুতর হচ্ছে তা ব্যাখ্যা করুন? ▶ এই শারীরিক সমস্যাগুলি আপনার জীবনে কীভাবে সমস্যা সৃষ্টি করেছে তা বর্ণনা করুন? ▶ দয়া করে আমাকে আপনার শারীরিক সমস্যার কোন উদাহরণ দিন যা এই মুহূর্তে আপনার জীবনে সমস্যা সৃষ্টি করেছে? ▶ ব্যাখ্যা করুন কিভাবে আপনি দৈনন্দিন জীবনে এই সমস্যাগুলি মোকাবেলা করছেন এবং মানিয়ে নিচ্ছেন?

	<p>বয়স্ক প্যারাপ্লেজিয়া ব্যক্তিদের মনস্তাত্ত্বিক অভিজ্ঞতা অন্বেষণ করা</p>	<ul style="list-style-type: none"> ▶ বৃদ্ধ বয়সে স্পাইনাল কর্ড ইনজুরি নিয়ে আপনার নিজের প্রতি কি অনুভূতি হয়? ▶ ব্যাখ্যা করুন কোন জিনিসগুলো চিন্তা করলে আপনার ভালো লাগে? ▶ দয়া করে আমাকে উদাহরণ দিন যে বিষয়ে চিন্তা করলে আপনার ভালো লাগে? ▶ ব্যাখ্যা করুন কোন জিনিসগুলো চিন্তা করলে আপনার খারাপ লাগে? ▶ দয়া করে আমাকে উদাহরণ দিন যে বিষয়ে চিন্তা করলে আপনার খারাপ লাগে?
	<p>বয়স্ক প্যারাপ্লেজিয়া ব্যক্তিদের সামাজিক অভিজ্ঞতা অন্বেষণ করা</p>	<ul style="list-style-type: none"> ▶ আপনি কি আমাকে বলতে পারেন আপনার সমবয়সী এবং সম্প্রদায়ের লোকদের সম্পর্কে আপনার মনোভাব কেমন? ▶ এই বয়সে আপনার সমবয়সী এবং সম্প্রদায়ের মানুষের সাথে আপনার সম্পর্ক কেমন তা বর্ণনা করুন? ▶ আপনার প্রতি তাদের মনোভাব কেমন তা ব্যাখ্যা করুন? ▶ মেরুদণ্ডের আঘাত নিয়ে সামাজিক সুবিধাগুলিতে আপনার প্রবেশগম্যতা সম্পর্কে আমাকে বলুন? ▶ মেরুদণ্ডের আঘাত নিয়ে আপনার সামাজিক কর্মকাণ্ডে অংশগ্রহণ সম্পর্কে ব্যাখ্যা করুন?
	<p>বয়স্ক প্যারাপ্লেজিয়া ব্যক্তিদের পারিবারিক সম্পর্ক অন্বেষণ করা।</p>	<ul style="list-style-type: none"> ▶ আপনি কি আমাকে আপনার পরিবারের সদস্যদের সম্পর্কে বলতে পারেন? ▶ বৃদ্ধ বয়সে আপনার পরিবারের সদস্যদের সাথে আপনার সম্পর্ক কেমন তা বর্ণনা করুন? ▶ মেরুদণ্ডের আঘাতের কারণে পরিবর্তনের জন্য আপনার পরিবার আপনার সম্পর্কে কেমন অনুভব করে? ▶ এই বৃদ্ধ বয়সে আপনার পরিবারের সদস্যরা আপনার কী কী বিষয়ে যত্ন নিচ্ছেন? ▶ আপনি কি আমাকে বলবেন এখন পরিবারের প্রতি আপনার ভূমিকা এবং দায়িত্বগুলো কি কি? ▶ পরিবারের সাথে একটি কার্যকর সম্পর্ক বজায় রাখতে আপনি কীভাবে আপনার পরিবারের প্রতি আপনার ভূমিকা এবং দায়িত্ব পালন করছেন?

সমাপ্তি মূলক প্রশ্ন

- ▶ মেরুদণ্ডের আঘাতের সাথে আপনার অভিজ্ঞতা সম্পর্কে আপনি কি অন্য কিছু যোগ করতে চান?

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: "Lived experience of elderly individuals with paraplegia"

Name of student: Farha Hossain Emu

Name and designation of thesis supervisor: Md. Julker Nayan
 Associate Professor & Head of Occupational Therapy Department
 Centre for the Rehabilitation of the Paralysed (CRP)
 Savar, Dhaka-1343, Bangladesh.

Appointment No	Date	Place	Topic of discussion	Duration (Minutes/Hours)	Comments of student	Student's signature	Thesis supervisor signature
1	22-08-22	CRP, office	<ul style="list-style-type: none"> • Research Title • Aim and objective 	45 min	Generating idea about mentioned topic	Farha	
2	29-08-22	CRP, office	<ul style="list-style-type: none"> • Background 	1 hr	Get idea about how to write background	Farha	

3	03.09.22	CRP, office	• Research proposal	15 min	Understand and raise idea about research proposal write up.	Fairly	[Signature]
4	10.09.22	BHPI	- Interview guide - Aim and objective	30 min	Understand and get clear idea about how to write interview	Fairly	[Signature] 10.09.22
5	20.12.22	BHPI Room-102	Data analysis	30 min	Clear understanding about mixing theme and sub theme	Fairly	[Signature] 20.12.22
6	18.01.23	BHPI	Research Draft feedback	1 hr	Not clear understanding about write up mistakes in research draft.	Fairly	[Signature] 18.01.2023
7	12.09.23	BHPI	Research Result feedback	1 hr 20 min	Clear idea about theme and sub theme. get idea about refine the draft.	Fairly	[Signature] 12.09.23
8	1.03.23	BHPI	Research result feedback	30 min	Not clear understanding describe the theme and sub theme	Fairly	[Signature] Summed
9	1.05.23	BHPI	Research Abstract feedback	15 min	Get connection of Abstract part	Fairly	[Signature]
10	31.5.23	BHPI	Research final draft feedback	30 min	Get connection of formatting and wording mistakes	Fairly	[Signature]
11	31.5.23	BHPI	Research final draft feedback	30 min	Get connection of formatting	Fairly	[Signature]
12							
13							

Appendix E: Narrative of the Interviews

Abraham

Mr Abraham is a 76-year-old male participant with paraplegia, living in a village of Birulia union. He was injured with incomplete paraplegic SCI when he was 60 years. This incident happened when he fell from the roof of the tin shed house. He was a carpenter before the incident. After discharge from CRP, he did not return to any work. His economic condition was not good at all but his family members were supportive towards him.

Although Mr Abraham able to walk without any assistive device but sometimes it becomes difficult due to illness. His home environment is not suitable for him. I observed that the front yard of his house was not paving which gets muddy in rainy days that can increase the risk of fall. However, the main road in the village made with pitched and the local transport were available all the time.

Amir

Mr Amir is a 61-year-old participant with paraplegic SCI. He lived in a village of Dhamshona union. He was injured with complete paraplegic SCI when he was a young boy of 18 years old. This incident happened when he carried out an overloaded sac of rice. After taking long-term rehabilitation service from CRP, he returned to work as a carpenter. He engaged with his job as a carpentry still now in old age and trying his best to fulfil his responsibilities in work place.

Mr Amir use wheelchair as an assistive device to move. The road to his house was uneven and broken. Even his home environment was not fully wheelchair accessible. Although the front yard of home was wheelchair accessible. But inside the house, I observed that the

wheelchair is difficult to operate due to the small room space. I also visited his workplace where I noticed that there was very little space to move the wheelchair.

Ikhlas

Mr Ikhlas is a 62-year-old male participant with paraplegia, living in a village of Savar union. His condition was non-traumatic incomplete paraplegia which was affected by tuberculosis (TB) when he was 55 years old. He had a business of import and export before the incident. After discharge from CRP, he chosen to carried out a business of selling and delivering packet of tea leaves in different shop and hotels.

Mr Ikhlas lived alone in a rented house without his family. The home environment was not wheelchair accessible wheelchair accessible. The road in front of his house was uneven and made of bricks. I observed that he made a slope to move wheelchair over the stairs with some piece of wood in front of his room, which has possibility of accidents at any time. I also observed that everything in his room was messy. A paid helping hand comes once a day only to cook meal. Although he had adapted to his lifestyle but living alone at home was difficult for him.

Kafi

Mr Kafi is a 65-year-old participant with incomplete paraplegic SCI. He lived in a village of Dhamshona union. He was injured when his foot slipped from the roof of the tin shed house. when this incidence happened, he was 51 years old. He had a job on film industry before the incident. After discharge from CRP, he did not return to any work. The current earning members of the family are his son and daughter-in-law.

Mr Amir use walking stick as an assistive device to walk. The home environment was suitable for him. But the road to his house was broken and muddy. I observed that it was

difficult for him to walk with a stick on the broken road. Even the transport is not available all the time due to poor condition of the village road.

Krishna

Mr Krishna is a 63-year-old male participant with paraplegia, living in a rural village of Bongaon union. He was injured with incomplete paraplegic SCI when he was a young man of 21 years old. This incident happened after he fell from a tree at his house. He was a service holder in a government job before the incidence. After discharge from long-term rehabilitation service from CRP, he wanted to engage in a company as typewriter. But he deprived from the job opportunity. Then he got a job in a poultry farm next to the house. But now he has retired from all work due to illness.

Mr Krishna was not married and lived with his sister's home. The home environment was not wheelchair accessible. Because of that, he stays in his room most of the time. I observed that there are some stairs but no ramp for wheelchair access at the front of the house. Even Lack of transportation in that village was another major problem due to broken roads.

Mokbul

Mr Mokbul is a 61-year-old male participant with paraplegia, living in a village of Vakurta union. He was injured with complete paraplegic SCI when he was 54 years old. This incident happened after falling from a big mango tree. He was a mason before the incident. After discharge from CRP, he did not return to any work. His wife works in a garment factory who is only the earning member of the family.

Mr Mokbul lives in his own house. For that reason, his home environment was fully wheelchair accessible. I observed there was ramp in the front yard that were paved with cement. The main roads of the village were besides his house which was made of pitch.

The transport is available all the time from his home. Mr Mokbul spends his leisure time in the front yard of the house or sitting on the side of the village road. But sometimes he cannot go outside and lying his bed all day long due to sickness.

Motiur

Mr Motiur is a 63-year-old participant with paraplegic SCI. He lived in a village of Savar union. He was injured with complete paraplegic SCI when he was a young man of 21 years old. He was an electrician before the incident. One day he falls from an electric pole by electric shock. After this incidence, he received long-term rehabilitation service from CRP. He started business of selling seasonal crops such as rice, betel nut after discharge from CRP. The present economic condition of Motiur's family is good.

Mr Motiur use wheelchair as an assistive device to move. The home environment was wheelchair accessible. I observed there was ramp in the front yard but it is difficult for him to operate the wheelchair now due to sickness. The road of the village was pitched but broken. Mr Matiur always takes someone with him when he goes out of the house because of the fear of falling in broken road.