Experience of Performing Instrumental Activities of Daily Living at Community of Adults with Paraplegia following Rehabilitation: A Qualitative Phenomenological Study

By

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Dedication

Dedicated to my beloved parents

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List of Abbreviations

ADL	Activities of Daily Living
AOTA	American Occupational Therapy Association
BHPI	Bangladesh Health Professions Institute
CBR	Community Based Rehabilitation
CRP	Centre for the Rehabilitation of the paralysed
IADL	Instrumental Activities of Daily Living.
ICF	International Classification of Functioning, Disability and Health
IRB	Institutional Review Board
IGA	Income Generating Activities
MDT	Multidisciplinary Team
OT	Occupational Therapy/Occupational Therapist
PWD	People with Disability
QWB	Quality of Well-being
SCI	Spinal Cord Injury
UTI	Urinary Tract Infection
W/C	Wheelchair
W/F	Walking Frame
WHO	World Health Organization

Abstract

Background: Instrumental Activities of Daily living are essential for leading an independent life with quality of well-being. However, there needs to be more evidence of IADL practice in developing, low and middle-income countries for people with SCI. In Bangladesh, people with SCI increasing day by day. The mortality rate at post discharge period is high in developing, low and middle-income countries rather than high income country. This study aims to explore the experience of performing instrumental activities of daily living in the community of adults with paraplegia following rehabilitation.

Method: The phenomenological study design of qualitative research was used to explore the personal experience of eight participants with spinal cord injuries who completed a rehabilitation program from CRP, recruited through purposive sampling. The self-developed semi-structured guide was used face-to-face for conducting interviews. The interview timing for individuals was 40 to 50 minutes, audio recorded and transcribed verbatim. According to Braun and Clark, the data analysis approach was inductive, followed by a six-step thematic analysis.

Results: Six males and two females were paraplegic in this study. The study's findings were facilitators or barriers to performing IADL. Eight main themes represent the study findings;1) areas of IADL, 2) physical health issues, 3) enablers to IADL performance, 4) barriers to IADL performance, 5) intrapersonal skill effect, 6) safety awareness,7) social feedback,8) Income Generating Activities (IGA) and follow up.

Conclusion: The findings indicate that the multi-disciplinary team has a significant role in institutional rehabilitation services to engage the person with SCI in IADL. A supportive environment from the health care professionals, family, and community people can assist the person with SCI to perform IADL. An occupational therapist can educate the person with SCI about self-advocacy to ensure accessibility by cost-effective adaptation and modification, which facilitates the person with SCI to live independently within the community.

Keywords: Instrumental Activities of Daily Living, Performance, Community, Spinal Cord Injury, Rehabilitation.

CHAPTER I: INTRODUCTION

1.1 Background

Spinal Cord Injury (SCI) is a life-changing experience that causes temporary and permanent changes and limitations in mobility, strength, and sensation autonomic nervous system (Fuseini, Aniteye, & Alhasssn, 2019). The person with SCI experience motor, sensory, bowel and bladder functional disorders, the main factors of disability in everyday life (Maribo et al., 2020).

Paraplegia refers to impairment or loss of motor and sensory function in the spinal cord's thoracic, lumber, or sacral segments without cervical and subsequent damage to neural elements within the spinal canal. It depends on the severity of the injury with paraplegia whether the pelvic organ, leg, and trunk are involved (Rupp et al., 2021).

The number of SCI patients admitted every year is about 390. From 2011 to 2016, records of people with SCI were taken from the medical records of the CRP.86.8% of the total respondents were men, and 13.2% were female. Traumatic paraplegia was identified in roughly 52% of cases (Rahman et al., 2017).

SCI hampers public health and human rights. Less than 0.1% of the population has a person with SCI, while 15% is affected by disability. When people are mature enough to obtain health care and rehabilitation service, they can reclaim their independence and contribute to their families and societies. A society that is friendly to people with SCI, in particular, will inevitably be more accepting of people with SCI disabilities in general (WHO 2013).

The public’s primary concern in Bangladesh is spinal cord injury. SCI in Bangladesh is based out of the Centre for the Rehabilitation of Paralysis (CRP). The largest acute

SCI unit in the world is CRP. There are four service phases for SCI in the inpatient unit: acute phase, active phase, rehabilitation phase, and community reintegration at CRP (Rahman et al., 2017).In Bangladesh as well as the rest of Asia, SCI is still a significant contributor to disability. People frequently experience potentially fatal complications. The patient can help themselves reintegrate into the community by receiving the proper care and specialised rehabilitation. Numerous governmental organizations in Bangladesh work with People with disabilities. Only one non-governmental organization, CRP, offers specialized services for SCI (Islam et al., 2011).

Rehabilitation services aim to maximize functioning and enable the client to reintegrate into society as independently as possible. The chances of a person with SCI being able to contribute to society are slim without access to rehabilitation and assistive technology. Making sure capable people carry out daily tasks is possible with a suitable assistive device. Otherwise, people with disability will not be able to do anything, reducing their functional limitations and dependency. In low-and middle -income countries, only 5 to 15 percent of the population has access to assistive devices that meet their needs. Specialized training and abilities among those who provide medical care and rehabilitation services (*WHO*, 2013).

The strategy of community-based rehabilitation (CBR) benefits people with disabilities in their local area. It promotes the integration of people with disabilities into their communities. Additionally, it helps to fill the gap in services for the person with disable in their neighbourhood. CRP began its CBR initiatives in 1996 to raise community awareness of disability issues and the need to follow up with individuals who had sustained spinal cord injuries. Currently, CBR activities of CRP, working closely with people with SCI and their families to overcome physical sociological

barriers in their communities through a holistic approach to the person and their environment (*Rehabilitaion*).

The daily pursuits that people regular engage in are their occupations and occupational activities. Occupations are regular, personalized activities that people engage in as individuals, families and communities to pass the time and give their lives meaning and purpose. Activities are planned and chosen to support the growth of performance abilities and performance patterns to improve occupational engagement. ADLs, IDALs, rest, sleep, education, play, and leisure are just a few of the many tasks that can perform as a part of a job. The complex task that supports daily life at home and community are known as care of others, managing the community, managing transportation with in the community, managing finances, maintaining one's health, managing one's home, preparing meals, cleaning up after one's meals, managing one's spiritual and religious activities, and managing safety and emergency maintenance (AOTA, 2014).

1.2 Justification of the Study

The experience of people with SCI returning to the community and performing activities after completing rehabilitation service is most important regarding the outcome of rehabilitation service.

Returning to social and community participation following SCI is identified with three main stages withdrawal, re-emergence into society, and stability (Barclay et al., 2018). When people with SCI return to their community after completing rehabilitation facing various challenges in the living area as physical, social, mental, and environmental in our country. A person with SCI might feel miserable and frustrated about the future and feel like a burden to others(Elahi, 2018). Now a day,

SCI is a common disability in all developing and developed countries in the world and is increasing daily due to a lack of awareness. As a developing country trying to develop a healthcare system and economy, it is essential to regard the experience of people with SCI who have returned to their community after completing rehabilitation. Returning community SCI is a serious cause of disability and mortality. People with SCI in Bangladesh die soon after discharge, and those who survive experience life-threatening secondary health complications(Hossain et al., 2021).

Exploring the experience of living with an IADL person with a spinal cord injury after returning to the community is vital regarding the rehabilitation service. Rehabilitation also enables individuals to participate in daily activities, remain dependent at home, and minimize the need for financial and caregiver support. To live independently, we must be independent on ADL as much as IDAL. Adults are the human resources of a country. Appropriate rehabilitation makes them a national resource, not a burden. Unfortunately, there is no available evidence base study currently in Bangladesh about the IADL of a person with spinal cord injury. Bangladesh is a developing country where many people live under the poverty line. Undoubtedly disability is the burden of a family besides poverty. Every person with a spinal cord injury should have self-dependent according to their ability with an assistive device and adaptive technique. The findings of this study for the health professional, especially occupational therapists, identify the level of performance.

1.3 Operational Definition

1.3.1 Spinal Cord Injury

Spinal Cord Injury (SCI) is a severe condition that disrupts a patient's physiological, mental, and imperial social well-being and exerts a tremendous financial burden on patients, their families and society (Yuan et, al. 2018)

1.3.2 Instrumental Activities of Daily Living

According to AOTA et al., 2014, Instrumental Activities of Daily Living (IADLs)are done daily to care for oneself and home. IADLs are more complex than ADLs. Activities to support daily life at home and community are often more complex interactions (AOTA, 2014).

1.3.3 Performing Activity

Performing refers to doing a task or action, especially a complicated one. It may occur in daily activity. Activity is a situation where many things are happening and being done (Wang et al., 2019).

1.3.4 Community

A community is a social group of units whose members live in a particular area, have specific characteristics and share a common culture, norm, religion, values, custom, and identity. They share a common geographic location, culture, or heritage.

1.4 Study Question, Aim and Objectives

1.4.1 Study Question

What is the experience of performing instrumental activities in daily living in the community of adults with paraplegia following rehabilitation?

1.4.2 Aim

The study aims to explore the experience of performing instrumental activities of daily living in the community of adults with paraplegia following rehabilitation.

1.4.3 Objectives

- To find out the self-dependency of health management and maintenance.
- To find out the self-dependency of home establishment and management.
- To find out the self-dependency of shopping.
- To find out the self-dependency of meal preparation and clean up.
- To find out the self-dependency of community mobility.
- To find out the self-dependency of financial management.
- To find out the self-dependency of communication management.

CHAPTER II: LITERATURE REVIEW

This literature review chapter overviews the findings of a few articles about IADL performance among persons with SCI. This chapter discussed the evidence for IADLs and importance in daily life, performing IADL with a disability, facilitators of IADLs performance, barriers to IADL performance, rehabilitation service and IADLs and the critical gap of the evidence.

2.1 IDALs and Importance of IADL in Daily Life

The instrumental activities daily living, such as caring for others, managing communication, managing driving and community mobility, managing finances, managing health, maintaining one's home, preparing and cleaning up after meals, managing one's spiritual and religious activities, maintaining safety and emergency and shopping were done through a systematic review. The ability of the client to function and live independently depends on both IADLs and ADLs (Hopkins et al., 2017). The use of the telephone, food preparation, laundry, house-keeping shopping transportation (including driving), responsibility for own medication, finance management were determined to be the most crucial IADL according to Lawtone scale for older adult (C.Millán-Calentia et al., 2010; Hunter & Kearney, 2018).The IADL has a strong relation with quality of well- being (Andresen et al., 1999). IADLs were important occupations required to perform 50% of their duties at home and rest of community. In the context of IADLs assessment and intervention, the authors emphasized the significance of IADLs taking into account the client's role, values, and priorities. A phenomenological study in South Africa on driving about fourteen SCI drivers' experiences were investigated. Occupational therapy select the goal for client during treatment and rehabilitation process, like meal preparation, home

management, shopping, transportation (Barclay, 2002; Barclay et al., 2018). Driving was a crucial IADL that ensured that many people could participate meaningfully in the community (Mtetwa et al., 2016).

2.2 Performing IADLs with Disability

The literature was shown physical and cognitive impairment that affected IADL in daily life (Hopkins et al., 2017).The strong correlation between IADL and QWB that found a cross-sectional study in midwestern U.S.A (Andresen et al., 1999).A qualitative study was conducted with people over 65 years, and participants were chosen randomly for both age and sex. About 65% of participants are classified as dependent in ADL, and 46%are independent in IADL based on their functional ability (C.Millán-Calentia et al., 2010; Suchy et al., 2010).The Swedish and UK literature on person with SCI were shown that physical activity increased the engagement of participation in everyday life as well as quality of life .The ability to perform ADLs and IADLs, those activities everyone must do regularly to live independently. Performing IADL in home and community quite challenging for physical and psychological and, psychosocial, financial issues, infrastructure home, transportation, negative social feedback (Alve & Bontje, 2019; Cancelliere et al., 2016; Fuseini, Aniteye, & Alhassan, 2019).

2.3 Facilitators to IADL Performance

2.3.1Assistance and Support

A Canadian qualitative study findings identified caregiver and family members support, community support, social support assisted them to access to community life. Family members and care giver play an important role in the process of providing care for quality of life both during rehabilitation and after discharge (Jeyathevan et

al., 2019). The Switzerland literature on person with SCI finding was social support contribute vital role in quality of life (Carrard et al., 2021).

2.3.2Adaptation and Modification

The literatures findings on SCI were coping strategies, self-efficacy, adaptation with present condition, environmental improvements, modification home environment and work place for physical accessibility. Self-dependency must need for ensuring environment accessibility by modification (Hopkins et al., 2017; Khanjani et al., 2019; Livneh & Martz, 2014). The literature demonstrated a normal life could be led by simply acting differently, overcoming challenges, and making use of available resources (Griffiths & Kennedy, 2012). Across sectional community survey was conducted with in two countries, and the result how the changes varied depending on the country contexts (Reinhardt et al., 2020).

2.3.3 Engage in Productive work

The literature on SCI were shown that engage in productive work, empowerment is essential for psychological health and physical health and become more active in performing activities in home and community. With an emphasis on improving the quality of life for those who live with disable, the role of vocational rehabilitation services in life care planning. Rehabilitation and health care professionals recognised the value of empowerment or other productive endeavors and encouraged the creation of programs that are appropriate for meeting those requirements for PWD (Hilton et al., 2018; Nas et al., 2015).

2.3.4 Assistive device

Literatures found that assistive device; manual wheelchair, power wheel chair, walking frame, crutch for SCI paraplegia to move and perform activity in home and community level. People with SCI used mobility device for walking, moving indoor and outdoor and increasing the physical capacity that was essential component for successful rehabilitation. Wheelchair provided both physical accessibility and also as a transport. Power wheelchair were used mostly in high income countries instead of manual wheelchair (Fuseini, Aniteye, & Alhassan, 2019; Khanjani et al., 2019; Salter et al., 2010). A Swiss literature showed that the use rate of mobility device on SCI; arm brace(53.2%), power wheelchair(47.3%), lowest for crutches (11.4%), and manual wheelchair(4.8%) (Florio et al., 2015). The use of assistive device vary socioeconomic condition and infrastructure of a country.

2.4 Barriers to IADLs Performance

2.4.1 Physical Health Issues

The literatures were found that the physical health issues were pain, bladder and bowel problems, pressure ulcers, and neurological symptoms like muscle spasm. Physical health hamper participation in everyday activities (Fuseini, Aniteye, & Alhassan, 2019; Griffiths & Kennedy, 2012; Jeyathevan et al., 2019). A cross sectional study with in 21 countries found muscle spasms (73.5%) and pain (77.3%) as a secondary complication and mortality rate increased in SCI because of pressure ulcer (Strøm et al., 2022).

2.4.2 Psychosocial Issues

Literatures were shown that anxiety, depression, frustration hamper mental health that comes from unfavorable society attitude, family members, community inaccessibility

like, a lack of wheelchair-friendly transportation, deprive from basic needs, financial issues (Griffiths & Kennedy, 2012; Reinhardt et al., 2020). Literatures south Asia Pakistan, India, Mongolia were shown that the women with SCI were socially, emotionally, and economically isolated. Conversely, males had full access to social and emotional support from their families and friends. Due to gender bias, women with SCI frequently experienced anxiety, depression, frustration and a pessimistic outlook on life (Mohan & Deb, 2022)

2.4.3 Financial Issues

Financial issues were not directly impact on everyday activity. The indirect effect on people with SCI limited participation all aspect of life because they could not afford to pay for health care and home environment modification (Mohan & Deb, 2022; Reinhardt et al., 2020). A North America study found that socioeconomic status impact on IADL related to Low-income and low-middle-income countries were the subject of the systematic review (Salter et al., 2010).

2.4.4 Physical Accessibility Issues

Literature findings were environment accessibility issues were home, kitchen, washroom, community, transportation, bank, shopping complex, road, but it greater problem in low in come country rather high income country (Jeyathevan et al., 2019; Mohan & Deb, 2022; Reinhardt et al., 2020). Iran literature ,the major issues of physical accessibility issues with SCI who moved with w/c home community infrastructure (Mohammadi et al., 2022). The residential area issues that the person with SCI in Urban get more environment accessible facilities rather than rural found by Canadian cohort study (Glennie et al., 2017).

2.5 Rehabilitation Service and IADLs

A qualitative semi-structured study in two hospital settings on rehabilitation of findings regarding health admiration and care support to effectively meet the needs of persons with SCI (Mohammadi et al., 2022). Previous literatures 2008 through 2016 were analysised in America on occupational therapy role in engage in IADLs and the findings were multidisciplinary service, home based care service, education on self-management. The study also explained the perceptions of participants and occupational therapists regarding the significance of IADL tasks for preserving community life (Hunter & Kearney, 2018). Follow up and IGA also included in rehabilitation service. IGA also helped overcome barriers and financial independent in their life (Islam et al., 2011; Tinta & Kolanisi, 2023). Occupational therapy worked how they engage the client IADL in rehabilitation process for as much as independent in daily life and occupational well-being (Andresen et al., 1999). SCI leads to severe disability and complications. Early rehabilitation was necessary to prevent disability and complications. Occupational therapy is an essential part of the rehabilitation process. In developed countries, occupational therapy is carried out by the occupational therapist in the rehabilitation team. This study also identified the necessity of including rehabilitation during the rehabilitation and discharge (Gaude & Vajaratkar, 2022; Jeyathevan et al., 2019). OT assess the patient's limitations and plan occupational activities. Occupational therapy is planned and implemented depending on individuals' social and cultural characteristics, level of education, personality traits, interests, values, attitudes and behaviours before and after the injury (Nas et al., 2015). The independence of functional activities like ADL and IADL increases morbidity and decreases the mortality rate. The literature clearly understood the person with SCI of IADL performance and patriation of the client environment (Salter et al., 2010).

Literatures were shown the effectiveness of community OT intervention, delivered alone or with a multi-disciplinary rehabilitation team, for improving occupational outcomes for adults with selected chronic diseases (Hunter & Kearney, 2018). Sixteen studies were met, and the significant difference between intervention and control groups for least one outcome of functional activities, functional-efficacy, social or work function, psychological health, general health, and quality of life. The literature evidence regarding the effect of the intervention on physical function and health OT can improve occupational outcomes in adult persons with disable (Hand et al., 2011).

2.6 Key Gap of the Evidence

Twenty kinds of literature were reviewed in this literature review chapter. All literatures were not directly related to my study title. But those are associated with this study.

- The population was above sixty or near sixty among the published literature thought they were persons with SCI maximum.
- There was qualitative and quantitative research study present. Though in qualitative research, the researchers used Lawton scale, but there were all IADLs domains were not included. In Lawtone scale and mental status questions were included.
- Limited studies were about persons with SCI, and the population group were different conditions such as Parkinson's disease, Multiple scoliosis, Parkinson's disease, Alzheimer's disease, and mental health condition.
- The publications years of these literature were shown from 2010 to 2020 but most relivant literature were 1999-2005. Recent was included in this study, but these are reviewing a year of literature.

- In the literature, there was no specified IADL performance with a physical disability. All literature shows that IADL performance with physical disability and associated with other disabilities mental impairment i.e., older people, Stroke, Multiple scoliosis mental health condition: Bipolar mood disorder,
- The fourteen studies were reviewed which were conducted in America, Australia, Iran, Turkey, Africa, Canada, and west Asia. But no study on IADL performance in adults with SCI in south Asia mentioned Bangladesh.

There was no study on IADL performance with following rehabilitation that is important for patients to live independently, health professionals to provide rehabilitation programs and institutional community-based rehabilitation system.

CHAPTER III: METHODS

3.1 Study Design

Method

The student researcher used qualitative research design to conduct this study because the researcher can use participants' universal structure to make sense of their experiences. Qualitative research can explore the participant's views, insights, opinion, feeling, and beliefs. The qualitative research design used in this study was exploratory and descriptive to determine the experience of performing IADLs in a community of adults with paraplegia following rehabilitation (Liamputtong, 2017).

Approach

The researcher used a phenomenological because the approach studies obtain a more profound sagacity into how a participant feels about one's experience. The researchers interpret the participant's feelings, perceptions, and beliefs to summarise the phenomenon under investigation (Liamputtong, 2017). The phenomenological approach was appropriate for this study to collect actual data from person with SCI about experience of performing IADLs at community.

3.2 Study Setting and Study Period

3.2.1 Study Setting

The study was conducted at Savar and Asulia. The researcher collected data from the participant's home environment.

3.2.2 Study Period

- The study was conducted from April 2022 to March 2023.
- The data collection time was from 1st November 2022 to 30th November 2022.

3.3 Study Participants

3.3.1 Study population

The population of this study were adult paraplegia who lived in the community at Savar and Asulia upazila.

3.3.2 Sampling Technique

The researcher used a purposive sampling process to collect the data for this study. In this sampling technique, the investigator selects the population according to need. The entire sampling process depends on the researcher's judgment and knowledge of the context. (Mckoy & Boyd, 2022) This research had some inclusion and exclusion criteria, which is why purposive sampling is one of the ways to meet the same population for the study (Creswell& Poth,2018).

3.3.3 Inclusion Criteria

- Participants who were above 18 years
- Participants were a person with paraplegic wheelchair users
- Participants who lived at Savar and Asulia
- Participants who got rehabilitation services within the last ten years, from 2012 to 2022

3.3.4 Exclusion Criteria

- The participant with serious physical health issues was reported in medical notes
- Vulnerable mental health condition that was reported in medical notes

3.3.5 Participants Overview

In this study, eight participants were selected, both male and female, who lived in their community. In this study, six participants were male, and two were male according to the male-female ratio of taking rehabilitation services from CRP at Savar, Dhaka, Bangladesh.

Table 3.1

Participant's overview

Pseudo name	**Age (in years)**	**Sex**	**Injury type**	**Living status**	**Assistive device**	**Working status**	**Duration since discharge (in months)**
Kabir	33	Male	Complete	Rural	W/C	Farmer	17
Nobel	47	Male	Complete	Rural	W/C	Shopkeeper	3
Alim	32	Male	Complete	Semi-Urban	W/C	Unemployed	58
Robin	25	Male	Incomplete	Semi-Urban	W/C, W/F	Unemployed	37
Jakir	37	Male	Complete	Rural	W/C	Unemployed	48
Mubin	46	Male	Complete	Rural	W/C	Farmer	72
Sofia	35	Female	Incomplete	Semi-Urban	W/C	Homemaker	6
Rita	21	Female	Complete	Semi-Urban	W/C	Student	41

3.4 Ethical consideration

According to Helsinki, 2013

Ethical clearance has been taken from the Institutional Review Board (IRB) explaining the purpose of the research through the Department of Occupational Therapy, Bangladesh Health Professions Institute (BHPI). IRB form number CRP/BHPI/IRB/09/22/623. The permission was also taken from the social welfare office and OT SCI department before taking the participant's information for data collection.

3.4.1 Informed Consent

The student researcher explained the aim of the research to the participant who was willingly interested in participating, and their data was collected. Verbal consent was taken from the participant as they were interviewed.

3.4.2 Unequal Relationship

The researcher did not have an unequal relationship with the participants.

3.4.3 Risk and Beneficence

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

3.4.4 Power Relationship

The student researcher had not any power relationship with the participants

3.4.5 Confidentiality

The researcher ensured that the participants about maintaining confidentiality. Their name and identity were disclosed to anyone except the supervisor, and this statement was included on the information sheet.

3.5 Data collection

3.5.1 Participant's Recruitment Process

At first, the student researcher contacted the CBR department and fulfilled the official requirement. Then the participant list was collected from the CBR department, and the actual participant was selected according to this research's inclusion and exclusion criteria. Then the investigator selected participants by purposive sampling who had returned to their community after completing rehabilitation service from CRP to conduct this study.

3.5.2 Data Collection Method

The student investigator conducted an in-depth semi-structured interview to collect data through face-to-face interviews in the participant's community.

The purpose of the study was to explore experience; an In-depth semi-structured interview was used for investigating complex behaviours, opinions and emotions and collecting data on diverse experiences. The researcher gets more accurate information by observing changes in participants' tone, experience, and word choice (Liamputtong, 2017). Through the face-to-face interviews, the investigator captured more accurate screening of verbal and non-verbal cues, including body language, emotions, and behaviours. The entire interview was conducted in Bangla, and all explained all questions for the participants' better understanding. The student researcher went to the participant's community and conducted a face-to-face interview. Before the interview, there was a formal agreement and statement between the researcher and the participant. The researcher has taken permission in the consent with signature before conducting the interview. After obtaining written consent, each participant was interviewed for 40 to 50 minutes. Eight participants' interviews were

face-to-face in their community. Interviews of participants were recorded by phone audio recorder. Recording and taking observational notes is essential for transcribing participant' interviews (Archibald et al., 2019). All notes have been taken of non-verbal communications during the data collection process to ensure that every aspect of the data was captured and helped to analyze in this study. The data collection was concluded when the same information came in the interview.

3.5.3 Data Collection Instrument

A self-develop interview guide was used in this study. The interview guide was developed by seven Instrumental activities of Daily Living according to AOTA. The questions in the interview guide help to find in-depth information from participants about the experience of performing instrumental activities of daily living in the community of adults with paraplegia following rehabilitation.

3.5.4 Field Test

After getting approval to conduct the research, the researcher accomplished the field test with two participants before starting the final data collection. The field test was essential to change the researcher's actual questions. There was no change in the interview guide after the field test.

3.5.5 Field Note

Th student researcher took observational notes about the home environment and the participant's moods and expressions. The field note helped to analysis data. The field note of all participants is included in the appendix: D.

3.6 Data Management and Analysis

The thematic analysis is an excellent approach to research where the researcher can find out something about the participant's views, knowledge, opinions, experiences, or values from the qualitative data (Braun & Clark, 2013). The researcher wanted to explore the experience of performing instrumental activities in daily living in a community of adults with paraplegia following rehabilitation. The inductive approach is also used in this analysis. So, the thematic analysis method was appropriate for this study. The student researcher analyzed the data using the thematic analysis method described by Barun and Clark (2016).

According to Braun and Clark's six phases of thematic data analysis, the researcher followed step by step for analysis are described below.

Step 1: Familiarizing yourself with your data

In this step, the student researcher listened to the interviews several times from the phone recording to familiarise with the collected data, transcribed data verbatim in Bangla and translated them into English. Then the researcher transcripted all participant's interviews which checked by supervisor. Moreover, the four interviews' data was translated by a different individual who was not present in the study setting, and they did not know about the aim or objectives of the research. The student researcher also checked the translation, which different individuals translated. The researcher translated four data from interviews. Each transcription was translated into English from Bangla transcription. The student researcher read all the data repeatedly to find out the participants' actual meaning, including the expression of what was noted in the interview period and the essential ideas.

Step 2: Generating the initial codes

The student researcher marked the essential and interesting data and wrote it down for individual participants. The researcher generated initial codes and collated data relevant to each other.

Step 3: Searching for themes

The student researcher found the themes by collating codes that were relevant to each code. Then the several codes were combined into a single theme.

Step 4: Reviewing themes

The researcher checked the codes and generated a sub-theme and theme of the analysis. Then the themes were set to ensure the usefulness and accuracy representation of data and also compared themes against each other. Then the themes were set to ensure the usefulness and accuracy representation of data and also compared themes against each other. The themes and sub them also checked with the supervisor.

Step 5: Defining and naming themes

The student researcher defined and named the theme so that readers can easily get an idea of what is understanding and figuring out by the theme. It was also checked with the responsible supervisor.

Step 6: Producing the report

The researcher produced the result according to the theme and sub-theme and started writing up steps.

3.7 Trustworthiness

The trustworthiness of qualitative research is crucial to the usefulness and integrity of the findings. It was maintained by methodological and interpretive rigour (Fossey et al., 2002).

3.7.1 Methodological rigour

- **Congruence:** The study aimed to explore the experience, and the phenomenological approach of qualitative research design was fit for achieving the aim and objectives (see section 3.1: Study design).
- **Responsiveness to social context:** The study conducted face-to-face interviews that met the real-life situation in their community and communicated with participants. The student researcher became familiar with the context (see section 3.2: Study setting).
- **Appropriateness and adequacy:** The purposive sampling technique was used to identify participants and search to inform the research question being addressed. The data collection method was in-depth observational semi-structure (see sections 3.4 and 3.5.1: Sampling and recruitment) for details explanation.
- **Transparency:** The student research was conducted systematically with supervision under the supervisor. The original data gathered were consistent, and the total data were relevant for this study. During the interview and data analysis of data, the researcher did not try to influence the process with her biases, values, and own perspectives. The researcher asked open-ended questions during the interview and took emotional expression (see sections 3.5 and 3.6: Data collection and Data analysis)

3.7.2 Interpretive rigour

- **Authenticity:** Participants' views are presented in their voices which are verbatim quotes presented. The researcher used Bangla and English language because Bangla is the first language and English is the academic language. The researcher summarized the answer to the participants for a recheck. Member checking was not possible for inadequate time (see section 3.6: Data analysis).
- **Coherence:** The findings were fitted to the research aim and objectives and the total data from which it was kept. The initial coding was checked with the supervisor (see section 3.6: Data analysis)
- **Reciprocity:** The supervisor checked all the study's data analysis steps and gave feedback. There was no chance of biases because the findings of the study were neutral that based on the spontaneous response of the participants and not any potential bias or personal motivation of the researcher (see section 3.6: Data analysis)
- **Typically:** The findings of the study were related to other contexts, circumstances, and situations in South Asian countries which are similar to Bangladesh (see section 3.6: Data analysis)
- **Permeability:** Every step of data analysis was audited to provide a rationale for discussion with the supervisor and maintain transparency. The student researcher checked all the data several times so that no information was missed. There was no personal interpretation of the researcher that influenced the outcome in the result (see section 3.6: Data analysis)

CHAPTER IV: RESULT

Eight main themes were emerged from the data analysis. The themes were i) Areas IADL ii) the enabler to IADL performance, iii) the barrier of IADL performance, iv) physical health issues affecting IADLs, vi) intrapersonal skill to perform IADL vii), safety awareness, vii) social feedback, viii) Income Generating Activities (IGA) support and follow-up. Each theme was associated with subthemes derived from data analysis except areas of IADL, physical health issues, intrapersonal skill to perform IADLs, safety awareness, and social feedback.

Table 4.1

Overview of Result

Themes	Sub-Themes
Areas of IADL	
Enabler to IADL Performance	Adaptation and Modification
	Assistance and Support
	Assistive device
Barriers to IADL Performance	Financial Issues
	Physical Accessibility Issues
Physical Health Issues Affecting IADLs	
Intrapersonal Skill to Perform IADLs	
Safety Awareness	
Social Feedback	
IGA support and Follow up	Productivity
	Follow up

4.1 Theme One: Areas of IADL

The persons with spinal cord injury performed nine types of IDAL in the home and community. Most participants perform six types of IADL which were shown health management and maintenance approximately two hours in a day, home establishment and management approximately an hour, health management and maintenance approximately an hour, meal preparation and clean up for two or three times, about an hour or more in each time, shopping and community mobility one or more times in a day, financial management was one or more times in a week, and communication management was one or more times in a day.

Other IADLs were performed by very few participants which were care of others, religious observance, safety and emergency maintenance specific periods in a day, about an hour or more, but it varies from person to person. Nobel stated, “At first, I get up early in the morning. After that, I brush my teeth, wash my face, take breakfast prepared by myself, clean the room and yard, prepare meals, shop, work in my shop and wash clothes.” He did most of the work alone because his family was not staying with him. Sofia shared, “I wake up, then tidy up the house, chopping vegetables, washing clothes, exercising regularly, praying salat, taking care of my granddaughter.” Jakir said, I cannot do any type of work in my house except saying a prayer (Client shared with a great sigh).” Other participants shared the same as them.

4.2 Theme Two: Enabler to IDAL Performance

Some things were identified which enabled the participant to perform IADL. Participants share their experiences on how they performed their IADLs: adaptation and modification, assistance and support, and assistive device. Accordingly, the related sub-theme is described as follows:

4.2.1 Sub-theme One: Adaptation and Modification

Adaptation and modification of environment and object were identified among the participants in order to perform IDAL as much as possible independently. Participants restructured their physical environment, which helped them perform IADL and used changing techniques to perform the activity. Participants had adaptability to physical disability, modification, and changing environments.

The adaptabilities of physical disability were perceived as adaptability and adaptability with a negative attitude. Some modifications were identified from participants' experiences: activity modification, object modification, and environment modification. The activity modifications were an alternative way of washing clothes, cleaning up utensils, online shopping, paying the bill and online banking, using adaptive strategies, i.e., rinsing utensils in a big bowl, cutting vegetables to putting a fish knife under the wheelchair cushion, washing clothes on the knee, bucket, table and hitting on washroom wall. Sofia stated, "I take a big bowl and rinse the dishes in it, sitting on a wheelchair in the drawing room. I feel good whenever I do any work by myself, and then my daughter-in-law washes it from the basin." Alim shared, "I wash my light weight clothes. I wet my clothes with washing powder in a bucket. Then I rinse them keeping them on my knee or through the wall."

Object modification was one of the modifications. Object modification also assists easier for the participant in performing IADL. The object modifications were a long handle broom, a stick using reaching something, and tools. Nobel stated, "Yes, I clean my room because the sweep and mob are long handles that suit me." Sofia said,

> "I cut all things sitting in the wheelchair. Even I can cut everything with a fish knife sitting in a wheelchair. My husband ordered the blacksmith to make the

> fish knife for me, which is appropriate for me. The fish knife handle is put under the cushion of the wheelchair. So, I cut vegetables, fish, and meat easily. I learned how to use the knife for cutting, but I was uncomfortable using it."

Environment modifications were making appropriate basin height by increasing and decreasing according to the sitting level of the wheelchair, changing the home environment by making a ramp and shifting ground level house, removing objects for the easy move with w/c and utensils, keeping spices jar in a convenient place for reaching from w/c, appropriate kitchen accessibility by removing threshold, placing stove at w/c level. Washroom accessibility by removing the threshold, adjusting the door lock, washing space modification by using tools with appropriate height, appropriating clothesline by downing, clothes iron space, Balcony modification by grab rail and removing obstacles for exercise, and the multi-plug system quickly to meet the need, i.e., nearer to bed. Nobel stated, "There is a ramp which I use to get down from my veranda to yard with a wheelchair.'' Rita said, "The kitchen of my house is suitable for me. Necessary items are within reach. After coming from CRP, I took it suitable for myself telling to my father (with smiling)". Kabir stated, "After coming from CRP.I made a high place to wash clothes so I can easily wash them sitting in wheelchair. I do not prefer to wash my clothes by others because I have poor bowel and bladder control".

4.2.2 Sub-theme two: Assistance and Support

Most of the participants shared their experiences with assistance and support for performing IADL. The assistance and support were family support, friends support, community people, and others assistance such as helping hand, paying labour. Identified family persons were wife, daughter, husband, mother, father, brother, son, daughter-in-law, and sister-in-law. Most of married individuals got support from their

spouses. The others get help from their other family members. They got physical and mental support both from them. Robin stated, “My wife gives me mental support always to perform any activity”. Nobel said, “I can cook rice, but I cannot pour rice starch. My helping hand pours the rich starch.” Dean shared,

> “If I feel bored and not feel good, then I call my friends at home…They are quite supportive to me, I think family and friends are a lot at this time. It is not possible to recover from any crisis without family. I eat and chitchat with them which makes me feel better…They console me.”

Rita said, “My father and brother help me cash out from the bank and bkash.”

4.2.3 Sub-theme Three: Assistive Device

Assistive devices also assisted in performing IDAL, which the participants reported. The assistive devices were a wheelchair (folding and fixed), backslab, and therapy equipment, i.e., dumble and TheraBand for hand strengthening exercises. Riva stated, “If the market is closer to my house, I go there with someone. I go to market by myself with the wheelchair for shopping.” Sofia stated, “I try to walk by the balcony grill of my rented house wearing a backslab. My husband took permission from the landlord for setting handles on the wall.”

4.3 Theme Three: Barriers to IDAL Performance

The two significant barriers were noticeable from the experience of participants performing IADL. The barriers were financial issues and physical accessibility which were described by subthemes.

4.3.1 Sub-theme One: Financial Issues

Financial issues, directly and indirectly, hindered the IADL performance of participants. Some participants shared their experiences of lack of money directly

affecting performance. Some participants needed adequate money for modification. Home environment modification and assistive device. Another participant shared that they needed money for their treatment purpose because how could they work if they were not physically fit. Alim stated,

> "This house is new, and still its structure is not complete and inappropriate for moving with my wheelchair. There is open space in the yard but an uneven surface. I need money for this work but I have no extra money (Client shared with frustration)''.

4.3.2 Sub-theme Two: Physical Accessibility

Almost participants described the environment was inaccessible where they wanted to participate in all activities and live independently, but their physical accessibility was a significant barrier to living independently. Most of the participants shared their experiences about physical accessibility issues: home accessibility, community accessibility, and transportation accessibility.

Some participants ensured home accessibility by home environment modification but were not. A few participants identified home accessibility issues that impeded IADL performance. The identified home environment accessibility issues were the washroom, kitchen, door, stairs, and yard. It was observed that those who lived in their own house had somewhat modified their homes. However, participants who lived in a rented house could not modify everything according to their needs. Sofia had stair and door kitchen and washroom issues in her rental house. Sofia stated,

> "Every day my husband carries me on his shoulder from bed to bathroom because the room door is inappropriate for me. Then he puts me on the chair…He again carries me from the washroom to bed. Even he carries me

> down from stair on his shoulder if I go outside. Before he used to carry on his lap at that time, he faced back problem. So now he carries me on his shoulder."

Community accessibility issues hamper their outdoor activities reported by most of the participants. These were shops, roads, shopping malls, markets, and bank accessibility. Maximum roads were uneven, crowdy, muddy, and under water when it rained. It was challenging to propel the wheelchair and also risky. Jakir shared his experience,

> "I cannot go to market though I want because the road is very uneven and highly sloped. Once I am on that road, I overturned with a wheelchair when I tried to propel on the road... An incident could have happened that day (client shared with panic)".

Rita shared her experience with bank accessibility issues. Rita stated,

> "There was no lift in the bank, so my little brother took me on his lap from the first floor to the second floor. Since then, I have been given a card from the bank so that I do not have to go to the bank."

The common transportation included auto rickshaws, CNG, private cars, microbus, and buses. Though the private car was easy to access, it was not affordable to everyone. Most participants used auto rickshaws and CNG as transport to go nearer places. Maximum avoid bus as transport because it could be hazard and hassle. They did not feel comforted by people's expressions. Mubin shared,

> "Hey, what do you say? These are all local buses. They do not want any time to take passengers. They leave they bus before taking passengers. We are wheelchair users, so the bus will not stop for us. They think that what will be a

benefit to take them. On the other hand, they give half fare because the disabled fare is half''.

4.4 Theme: Physical Health Issues Affecting IADLs

Some physical health issues affected IADLs those were identified among the participants. Participants could not perform IADLs for physical issues. The physical issues included pressure ulcers, bowel and bladder incontinence, pain, muscle spasms, and urinary tract infections.

Some participants shared pressure ulcer experiences among the group of participants. Three participants reported still experiencing pressure ulcers. Jakir reported,

> "I have a pressure ulcer. My wife dresses every after two days. I was in the hospital a few days ago. I am apprehensive about it. I cannot sit and sleep properly. I cannot perform my daily activities like washing clothes, cleaning the room, shopping (Client shared worriedly)."

Some participants complained about bowel and bladder incontinence among the group of participants. They faced challenges in the management of bowel and bladder problems. The participant had bowel and bladder incontinence, and as a result, they did not mingle with people because they feared embarrassing themselves about incontinence bowl and bladder in a public place. So, the IADLs are related to the public, like shopping, community mobility, financial management, and communication management; these were avoided to perform. Kabir had this state,

> "My major problem is bowl and bladder timing. I feel embraced going outside because I have no control over my urine and faeces. Some days it was good timing for bowel and bladder, but it has gone...The urination was controlled for 3-4 hours, but it has also gone''.

Half of the participants complained about pain. The pain was the most devastating symptom they endured. They complained of a burning sensation of pain. The majority of the participants complained about muscle spasms. They faced automatic and sudden jerky movement of their leg. Some participants mentioned specific timing like morning and night. Others reported muscle spasms deteriorated with any touch, movement, touch, or irritation. Though they perform light activities, brushing, bathing, and eating than other activities, i.e., home management, shopping, meal preparation, financial management, and community mobility. IADL hamper more than ADL because time and effort need more than ADL. Alim reported,

> "Now I am suffering from muscle spasms, which have increased for some days, so I cannot do my work as before, and it increases in the morning…Nowadays I cannot do exercise on my leg because it increases. The first spasm affects both my leg and then spreads my full body. It badly affects my body even if I can't breathe properly. I urinate because of my tremor. My clothes get ruined for peeing rained."

Some patients complained of UTI, stones in the urinary tract and outlet obstruction. So, they did not physically feel good and could not perform IADL. Mubin reported, "I have a urinary tract infection, and the doctor diagnosed a stone in the urinary tract. I am continuing medicine for infection."

4.5 Theme Five: Intrapersonal Skills to Perform IADLs

Some positive and negative intrapersonal skills, and unrealistic desire were noted among the participants. Some positive skill inspired to perform IADLs and some negative demotivated doing IADL. A few participants shared positive intrapersonal skill such as, self-confidence, self-satisfaction, positive thinking, reality acceptance,

and awareness of self-capability that facilitate performing IADL. Most participants liked to be independent and felt great when they could do their work alone. Half of the participants among all were positive intrapersonal skills. Rita stated,

> “After the passing away of my mother, I had a pressure ulcer. Then I think this is how I have to move on by myself. If everyone can do it, why cannot I? So, I make myself as if I can do anything without others' help as much as possible”.

The majority of participants reported some negative intrapersonal skills on their performance. The identified negative sills were a lack of acceptance of reality, low self-esteem, insecurities, an inferiority complex, and frustration. Some participants were ashamed and felt inferior for their physical disability. Kabir stated,

> “I used to walk around with the people. Now they are walking in front of me like before, and I am with a wheelchair. It makes me upset when I see them. Really, I cannot take it. I feel ashamed that I use a wheelchair, I do not go outside with a wheelchair (shared tears with eye corner).”

Identified a few participants who had unrealistic desires about their recovery from this period. Nobel said,

> “As much as the environment of my house is adjusted with in this. I do not want to change anything anymore... I will not make an environment is suitable for my life by changing environment. I want to make myself for the environment without adaptation. I am hopeful that I will be able to walk very soon. I will go back to my previous life. Now I do not want to create my own customized environment (Client shared with annoyance)”.

4.6 Safety Awareness

Safety awareness was most important for the participant because they had already suffered many health-related complications. Further complication had posibility happened doing IADLs such as, burned at cooking activity, fall down high at household activity, excessive bending during washing clothes. Most participants shared that they and their families were also concerned about safety awareness to prevent further complications. Except for a participant who burned his feet putting into hot water for ayurvedic treatment. Participants reported a lack of awareness regarding safety about maintenance and self and family person concern about safety. Sofia shared, “My daughter-in-law and my family person do not allow me e to serve hot meals or carry. They are afraid of burning and its further complication. They think if there happens a significant danger while doing a job. Nobel stated,

> “Yes, I am very careful to touch anything hot on my body. I take a big towel on my knee before taking hot anything and put something on the table. People who are like me face a big problem whenever their skin is affected by a wound”.

4.7 Social Feedback

Positive social feedback, negative social feedback, socio-cultural beliefs of a person, and traditional thinking were included in social feedback. A few participants shared positive social attitudes encouraging them to perform outside activities. Nobel stated,

> “The shopkeeper helps to fill the bag with things according to my needs and they come to take money from me…Some people help me by giving me space and a chance to buy something prior but some or not. Some people help to overcome high bit pushing the wheelchair”.

The negative social attitude from society, negligence, criticism, and lack of social manners were observed by participant experience which hindered their IADL. Jakir shared,

> "My neighbour does not give me some space because I do not have enough space to take the wheelchair. Even there is no alternative option to go out without this way. My neighbour does not allow to raise the road with soil… I am poor as well as disabled. End of the day, they win and I lose. If the situation continues, I will not live much longer (Client shared with tears)".

Some participants shared their inferiority feelings. Rita shared, "I feel very inferior myself then. No matter how much you become smart, then how they look at me. I feel like I am unsmart."

Socio-cultural beliefs of the participants discourage performing some IADL. Some participant divided their work into female work and male work. A few participants thought that all household chores are housekeeping, laundry, and cooking, were female work. Some totally depended on their wife though they could work. Alim said,

> "I can but I have someone to do my work. So why will I do it. I will do my work when she does not present with me. I faced a lot of trouble in CRP… I had to do my work by myself even though it was difficult".

The traditional beliefs were taking traditional healer treatment and negative perception of society people about disability was prejudice identified from society people. Nobel stated, "I am bullying with speech. People say that my present condition is the punishment of my sins from God. Really, I do not know how much sin I have, So I am suffering".

4.8 IGA Support and Follow-up

Financial support for IGA, i.e., paid to shop, farming, providing assistive devices, home and workplace modification, i.e., ramp, providing assistive devices, i.e., wheelchair, training about IGA, i.e., shop management, gardening these were included in IGA support.

Most participants were grateful to CRP for CRP service, health professional positive attitude, learning acquirement i.e., transferring techniques, health education about preventing further health complications like pressure ulcers, bowel and bladder issues, and home visits. IGA support and follow-up strongly encouraged them to perform IADL because these made them self-dependent, confident, physically fit and properly utilise their time.

4.8.1 Sub-theme one: Productivity

All participants shared that productive life is most important, though two were not engaged in productive work. All IGA are productive work. They had got different training according to their ability from CRP. The identified productive works of six participants were shop management, farming, i.e., cattle farm, gardening, and crafting, i.e., jewellery making. Most of the participants had with their productive work but few had dissatisfaction. Nobel sated,

> "I am very grateful to everyone at CRP for their health care service and also financial support, training in shop management but except a profession who directly said never you cannot walk, at that I was throwing a plate and I cried a lot."

The dissatisfactions were difficulty in choosing appropriate productive work from limited IGA provided from CRP, inadequate financial support, and delayed needs

response. Kabir stated, “If you engage in work, your mind will be fresh and your health will also be good…I applied for financial support three months ago still, I do not get any response”. Other participants shared the same like them.

4.8.2 Sub-theme two: Follow up

Follow up system is maintained by home visit. Find out any health issues and provide support for treatment, i.e., pressure ulcers, bowel and bladder issues, providing health products, i.e., gel for catheterisation, psychological support, finding issues regarding the home environment, workplace and assistive device by hearing and observation. Participants also shared their great feeling that someone comes from CRP every year and knows their overall condition. There were satisfaction and dissatisfaction both present in the participant’s experience. Some participants were satisfied with the follow-up service from CRP. Mubin stated, “Every year, someone comes from CRP and knows about your life and any problem…I can share my problem and get a solution.” Participants shared their problem that sometimes it is solved and sometimes it is not. Jakir stated,

> “I am very poor. After the home visit, it was said to make a ramp for getting down from the veranda to the yard. It was made of soil. Now it is not appropriate for use with a wheelchair because it is damaged during rain. How often have I told them, but they did not respond”.

CHAPTER V: DISCUSSION

This study aimed to explore the experience of performing instrumental activities of daily living in a community of adults with paraplegia following rehabilitation. Eight participants participated in this study who were six male participants and two females among the participants. The study identified eight themes that emerged from the interview of participants.

In this study, overall performing IADLs were shown health management and maintenance, home establishment and maintenance, meal preparation and clean up, community mobility, financial management, communication management, and religious observance. Other studies show that IADL is similar to this study finding except for driving and the care of pets(Hopkins et al., 2017). Religious observance did not include another study. Most studies on IADL of Physical and cognitive impairment combinedly (C.Millán-Calentia et al., 2010; Charlifue et al., 2010; Fricke & Unsworth, 2001). At the same time, this study was only on physical impairment. However, the care of pet animal domains of IADL according to AOAT was not found in our country's context. There is a variation in the domain of IADL, such as culture, country, and sex basis.

The study identified physical health issues: pressure ulcers, bowel and bladder incontinence, pain, muscle spasms, and UTIs. Literature showed the same findings regarding health-related issues. The physical health issues were pain, bladder and bowel problems, pressure ulcers, and neurological symptoms (Barclay et al., 2016; Cancelliere et al., 2016; Fuseini, Aniteye, & Alhassan, 2019). Physical health issues directly created barriers to performing IADL.

In this study, the findings were identified adaptation with changes after injured and modification for ensuring accessibility, assistance and support mental support more than physical, and assistive devices which enabled to perform the IADL of a person with spinal cord injury. The literatures findings on SCI were coping strategies, self-efficacy, adjustment skill, modification of home environment and work place for physical accessibility. Self-dependency must need for ensuring environment accessibility by modification Performance and participation in activity were continually improving because of their better acceptance, accessibility, and assistive technology for building adaptation (Hopkins et al., 2017; Khanjani et al., 2019; Livneh & Martz, 2014; Stiens et al., 2002). The other literature findings were self-efficacy, adjustment skills, relearning capacities, and availability of cost-effective adaptive equipment for performing daily activities (Alve & Bontje, 2019).

Literature shows the need of assistance for most frequently heavy housework, financial management, shopping, and light housework. Though the literature found caregiver service home-based support paid and unpaid that assist the IADLs part-time. Caregiver support improves access to the community and increases social participation(Smith et al., 2016). But in this study's findings of assistance support maximum were unpaid family support, friend's support, community people, and personal assistance. Though a person with SCI needs assistance, sometimes inappropriate strategies for helping them. There was a state that a husband carried his wife on the shoulder. For this, the husband faces neck pain. It was a remarkable finding in this study. Home environment modification and assistive devices assist in performing IADL to minimize the effect of the changes after physical impairment (Charlifue et al., 2010). In this study, a wheelchair, power wheelchair, standing frame, crutch, and backslap assist in moving and performing IADL. The interesting findings

of this study were activity modification and object modification according to their context and comfort. Across sectional community survey was conducted with in two countries that shown the modification vary to different environment country contexts (Reinhardt et al., 2020).

This study found the barriers to IADL: financial and physical accessibility issues. However, the impact of financial issues was not directly on IADL's performance. This impact directly was on health care, modification, home adaptation, and equipment when necessary. The financial issue was identified as a secondary issue (Mohan & Deb, 2022; Reinhardt et al., 2020). The physical environment barriers were home accessibility, community accessibility, and transportation. Literature shows that limited financial resources for health care and poor environmental access are similar to this study. These barriers were claimed to impact physical health, limit activities, and restrict participation in all areas of life. Environmental barriers fluctuate in the environmental context (Dorjbal et al., 2020). Transport was a vital challenge for a person with a spinal cord injury (Barclay et al., 2018). In this study, maximum prefer personal transport and avoid long-distance journeys. They avoid public transport for their infrastructure.

In this study's findings, there were three types of intrapersonal skill to IADL performance which were positive, negative intrapersonal skill and unrealistic desire. The positive intrapersonal skills were self-satisfaction, self-confidence, positive thinking, reality acceptance, and awareness of self-capabilities. The findings literatures were living a normal life, just doing differently, overcoming challenges to determine success, and self-satisfaction with the situation (Griffiths & Kennedy, 2012; Livneh & Martz, 2014). Perceive physical disability with adaptation and self-adequacy with high moral perceived abilities returning to work (Fuseini, Aniteye, &

Alhassan, 2019). The negative skills were a lack of reality acceptance, low self-esteem, insecurities about life, an inferiority complex, frustration, and anxiety. The other literature findings on negative intrapersonal skills were similar to this study. The negative skills were sadness, depression, irritability, anger, suicidal thoughts, and lack of self-confidence (Fuseini, Aniteye, & Alhassan, 2019; Khazaeipour et al., 2014; Reinhardt et al., 2020). The difference finding of intrapersonal skills in this study from other literature was the unrealistic desire and hope for full recovery after completing institutional rehabilitation service. Another remarkable finding was the insecurity of life. A person stated that his perception was day by day decreasing my condition than death.

Safety awareness is vital for a person with a spinal cord injury to prevent further complications. Further health complications resisted their performance which was shown in this study. The safety awareness findings identified a lack of awareness regarding safety and maintenance and self and family concerns about the safety of activities and health. The negative impact of a lack of safety awareness in low-income country mortality rate is higher than in high-income county after discharge from the hospital which was health safety (Hossain et al., 2021). In this study, self-safety awareness and family concern about safety while performing activities and also their health care. In this study, people with SCI stated that they and their family concerned about them when they performed any activities. They and their family also concerned about their health safety to prevent further complications. However, all were not concerned about it.

Social feedback was identified in this study. The positive social feedback was positive attitude from surrounding people (Mohan & Deb, 2022). It is similar to this study. The negative social attitude, negligence, criticism, and lack of social manners

were shown as negative feedback from society which hindered their IADLs. Literature shows that negative social feedback, discrimination, stigma, negative attitude from society and family members, and gender bias (Griffiths & Kennedy, 2012; Mohan & Deb, 2022; Reinhardt et al., 2020). The negative social feedbacks were similar to this study. Socio-cultural beliefs of a person and traditional thinking were also identified in this study that kept them away from performing activities. Maximum males depended on their wives though they were capable enough to perform their IADL performance and divided work according to gender. These were markable findings in this study. In this study also remarkable finding was neighbor issues. A person with SCI does not go out to neighbor issues because they do not consider space for moving with a wheelchair.

Income Generating Activities (IGA) support and follow-up were found in this study. In this study, those involved in productive work are actively performing IADLs. Literatures shows the subjective quality of life, productive work, satisfaction with the performance of daily activities, and satisfaction with community integration. (Boschen et al., 2003; Hilton et al., 2018; Nas et al., 2015). This study stated that productive work gives earning sources mental satisfaction according to their ability. All participants shared that they got training opportunities from CRP according to their ability. Some people stated that various types of training should be included in CRP training so that they can choose appropriate work with comfort and satisfaction. CRP runs a follow-up program for those who have completed their rehabilitation service from CRP. Literature shows that follow-up programs prevent and manage secondary complications in high-income countries and their mortality rate is lower than in low-income countries (Hossain et al., 2021). Some participants shared that they did not follow up on service every year and did not get the solutions when they

shared their problems. However, a maximum of people with SCI were grateful to CRP for their rehabilitation service and still, they are getting service from CRP. Some financially unstable patients applied to their home environment modification to ensure wheelchair accessibility but received no feedback.

CHAPTER VI: CONCLUSION

6.1 Strength and Limitation

6.1.1 Strength

- The researcher followed the COREQ guidelines in this study.
- This is a new study area in Bangladesh, and there has been no investigation into this phenomenon.
- This study, which used qualitative methods to achieve its aim and objectives was appropriate for this. The study findings were appropriate to the aim and objectives.
- The findings of this study will aid in future research on this phenomenon.

6.1.2 Limitation

There are some limitations that the student researcher has considered during the time of the study.

- The investigator did not include all IADLs in this study for lack of study timing.
- Participants data was collected only from two areas (Savar and Asulia). So, it is difficult to represent the whole of Bangladesh.
- In this research, the participants were only persons with SCI who were paraplegic.
- There were not enough articles and literature about the experience of IADL performance in Bangladesh and South Asia. So, there was limited information related to this study.

6.2 Practice Implication

Institution based practice implication

In the rehabilitation setting, an occupational therapist generally assesses IADLs to determine individual performance and participation worldwide. After assessing, provide intervention according to their needs. An occupational therapist should assess the IADL performance and measure IADL participation. OT can promote engagement in IADL, and they should consider task-specified training for problematic IADL participation for a person's spinal cord injury. Occupational therapy should enable the client to engage in IADLs through advocacy and policy involvement to improve self-dependency and quality of life person with SCI living in the community.

Community based practice implication

The community people will be aware about needs, challenges, and rights person with SCI of in the community. The government awareness will increase on infrastructure of environment for person with physical disabilities that hamper every day activities independently.

6.2.1 Recommendation for future practice

- Working more closely with a person with SCI to minimize the risk of physical disability with a multi-disciplinary rehabilitation team approach during their rehabilitation service.
- Health professionals should provide knowledge about their client's health condition and their prognoses easily in a positive way.
- Health professionals should understand the client's importance of independence.
- An OT should suggest modification and adaptation according to their preference, capability, and comfort.

- Health professionals should ensure the psychosocial care of a person with a spinal cord.
- Providing education to healthcare professionals and clients to overcome challenges to determine success.

6.2.2 Recommendation for further research

- A quantitative study should be conducted on the IADL performance of a person with spinal cord injury.
- In this study, student researchers conducted the seven domains of IADLs. In future, it should become with other domains of IADLs.
- OT intervention enables IADL performance, participation, and client satisfaction in Bangladesh.

6.3 Conclusion

Instrumental activities of daily living allow a person with SCI to live independently in the community. The ability to perform IADLs assures greatly improves the quality of life in the community. Identifying factors associated with SCI would be advantageous for clinical practice. Health professionals must also focus on education about their health condition and proper guidelines to help clients live independently. Providing training under a multi-disciplinary rehabilitation team about adaptation to life changes and ensuring accessibility to the physical environment by modification. More concerns need to ensure appropriate modification with their preference in rehabilitation service and considering their financial capability and cultural context. The problems of a person with SCI are sought out in the community to perform activities after discharge by follow-up program and suggest self-advocacy to remove their problem. Using and building this evidence, occupational therapists and other

professionals in the MDT team can continue to promote their role in assistance to people with SCI in IADLs performance in their community level livelihood.

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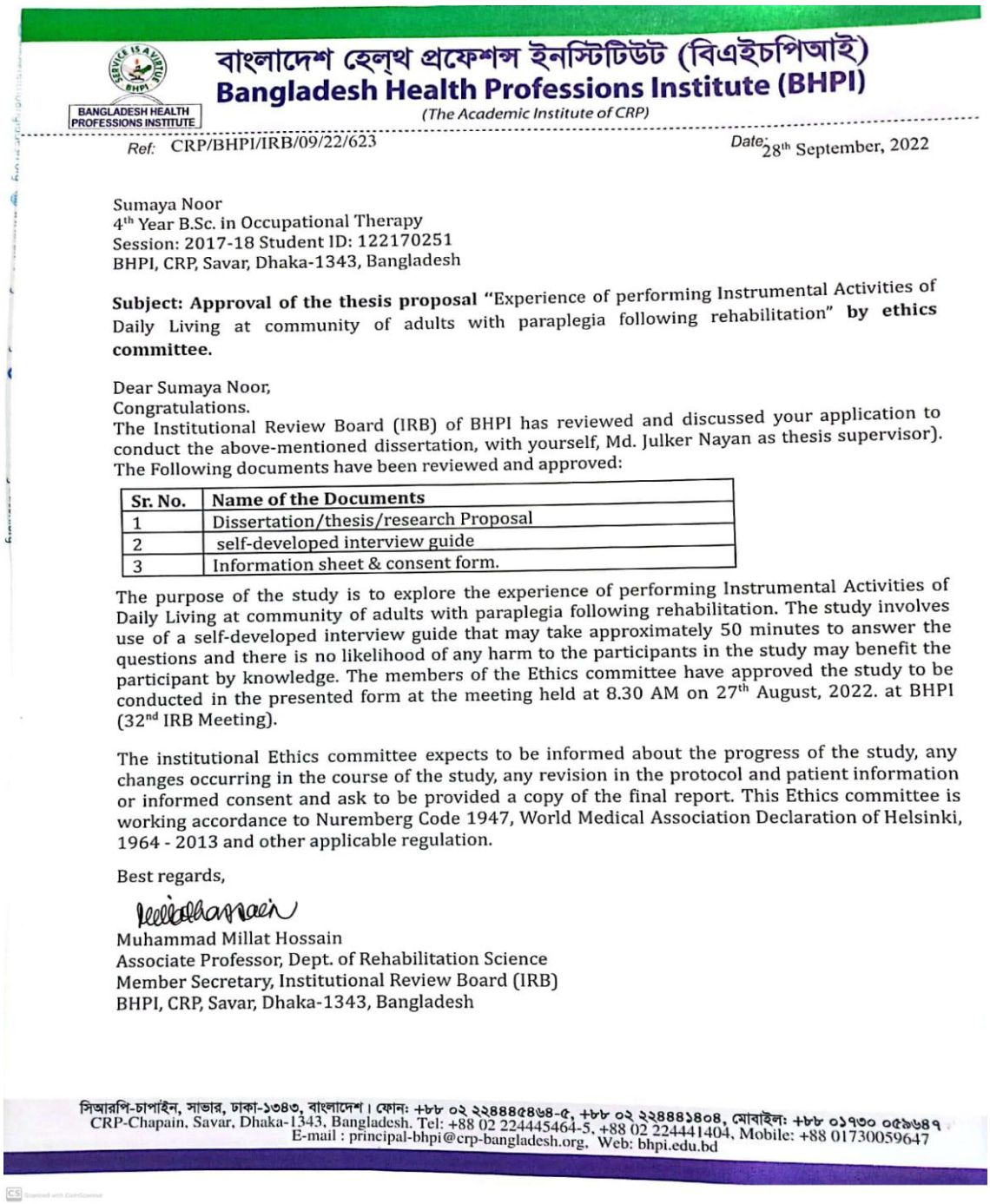
APPENDICES

Appendix A: Approval letter

Ethical Approval Form



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

BANGLADESH HEALTH PROFESSIONS INSTITUTE

Ref: CRP/BHPI/IRB/09/22/623

Date: 28th September, 2022

Sumaya Noor
4th Year B.Sc. in Occupational Therapy
Session: 2017-18 Student ID: 122170251
BHPI, CRP, Savar, Dhaka-1343, Bangladesh

Subject: Approval of the thesis proposal "Experience of performing Instrumental Activities of Daily Living at community of adults with paraplegia following rehabilitation" **by ethics committee.**

Dear Sumaya Noor,
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	Dissertation/thesis/research Proposal
2	self-developed interview guide
3	Information sheet & consent form.

The purpose of the study is to explore the experience of performing Instrumental Activities of Daily Living at community of adults with paraplegia following rehabilitation. The study involves use of a self-developed interview guide that may take approximately 50 minutes to answer the questions and there is no likelihood of any harm to the participants in the study may benefit the participant by knowledge. 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
Associate Professor, Dept. of Rehabilitation Science
Member Secretary, Institutional Review Board (IRB)
BHPI, CRP, Savar, Dhaka-1343, Bangladesh

সিআরপি-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

Date: 13th October,2022

To

The Head of the Department of Occupational Therapy,

Bangladesh Health Professional Institute.

Subject: Prayer for seeking to conduct the research project.

Sir,

With due to respect, I am seeking permission to conduct the research project as a part of my 4th year course module. My research title "Experience of performing Instrumental Activities of Daily Living at Community of Adults with Paraplegia following rehabilitation". The aim of the study is to explore the Experience of performing instrumental Activities of Daily Living at Community of Adults with Paraplegia following rehabilitation who become after complete rehabilitation service from CRP. Now I am looking for your kind approval to start my research project and 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 to grant me the permission of conducting the research and will help me to conduct a successful study as a part of my course.

I remain

Sir

Sumaya Noor

Sumaya Noor

4th year B.Sc. (Honours) in Occupational Therapy, BHPI

Attachment: Proposal of Research

Signature and comment of the supervisor	Signature and comments of Head of the Department of Occupational Therapy
13.10.22 Md. Julker Nayan Associate Professor Department of occupational Therapy Bangladesh Health professional (BHPI)	13/10/2022 SK Moniruzzaman Head of the Department of Occupational Therapy Bangladesh Health Professional Institute (BHPI)

I refer to this application to CRP

Date:13 October,2022

To

Head of the Rehabilitation Division

Centre for the Rehabilitation of the Paralysed (CRP).

CRP-Chapain, Savar, Dhaka-1343

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

Sir,

With due respect to state that, I am a student of 4th year B.Sc. (Honours) in Occupational Therapy of Bangladesh Health Professions Institute (BHPI). In 4th year I have to submit a research project to the University of Dhaka in partial fulfillment of recruitment of the degree of Bachelor of Science in Occupational Therapy. The area of my research is spinal cord injury and my research title is **"Experience of performing instrumental Activities of Daily Living at Community of Adults with Paraplegia following rehabilitation".** It is phenomenological qualitative research; I would like to take the interview of participants of SCI people who have already completed their rehabilitation program from CRP. That's why I need the address of the patient 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 of person with spinal cord injury who have completed their rehabilitation service from CRP and help me to complete the project successfully.

I remain

Sir,

Sumaya Noor

Sumaya Noor

4th year B.Sc. (Honors) in Occupational Therapy, BHPI

Attachment: Proposal of Research

Forwarded for your kind consideration and permission for data collection to conduct the Research project.

Sk. Mohammad Zaman
Associate Professor & Head
Dept. of Occupational Therapy
BHPI, CRP, Savar, Dhaka-1343

Appendix B: Information Sheet & Consent form

Information Sheet and Consent form (English)

Information Sheet

I am Sumaya Noor, student at the Bangladesh Health Professions Institute (BHPI) is the academic institute of the Centre for the Rehabilitation of the Paralyzed (CRP), Savar, Dhaka. I am studying 4th year B.Sc. in Occupational Therapy. In regard to the fulfillment of B.Sc. Degree, it is compulsory to conduct research in 4th year of study. I would like to invite you to take part in my research study and the title is" Experience of performing instrumental Activities of Daily Living at Community of Adults with Paraplegia following rehabilitation". The aim of the study to explore Experience of performing instrumental Activities of Daily Living at Community of Adults with Paraplegia following rehabilitation" The objective of this study is to find out self-dependency of using phone, shopping, food preparation, Housekeeping, Laundry, managing transportation, obtaining medication and taking them directly, Handling finance.

It is up to you whether or not you want to participate in this study. If you do not wish to take part. then there is an opportunity to withdraw your participation at any time. There is no incentive for participation in the study. May be there is no direct be harm and benefit for you. The information given by the participant will be maintained confidentiality. At the same time their name and identity will never be disclosed.

However. The study results obtained from the research will help the authorities to understand the experience of performing instrumental Activities of Daily Living at Community of Adults with Paraplegia following rehabilitation, which will help in the future to providing intervention of rehabilitation program person with spinal cord injury.

Self-developed interview guide recorded by Audio recorder. Confidentiality of all records will be highly maintained, and all details will be kept on a confidential information that is only accessible to me and my supervisor. The identity of you not to be disclosed in any presentation or publication without your agreement. If you have any queries regarding this study, please feel free to ask. I am accountable to answer all questions regarding this study.

Sumaya Noor

B. Sc. in Occupational Therapy, 4th year

Department of Occupational Therapy BHPI, CRP, Chapain, Savar, Dhaka-1343.

Consent Form

I am…… (Name of Participant), have read the above statement and understand the nature of my participation in the study. I understand that all interview data that will be used in the research will be kept confidential and secure. Only the researcher and supervisor will have access to the data and the data will be published anonymously. I am also aware that I may withdraw my participation within one month of the study. For this, I am not obliged to give accountability and compensation to anyone. I am aware of all the above information and agree to be a participant in this study.

Signature of Participant…….

Date……

Signature of the assignee……

Date……

Contact address of researcher:

Sumaya Noor

Mobile no:01742033554

E-mail address: sumayanoor24@gmail.com

Withdrawal Form

I am…… (Name of Participant), have read the above statement and understand the nature of my participation in the study. I understand that all interview data that will be used in the research will be kept confidential and secure. Only the researcher and supervisor will have access to the data and the data will be published anonymously. I am also aware that I may withdraw my participation within one month of the study. For this, I am not obliged to give accountability and compensation to anyone. I am aware of all the above information and withdrawing myself as a participant in this study.

Signature of Participant…….

Date……..

Reason of withdraw……

Signature of the assignee……

Date……

Information sheet and Consent Form (Bangla)

তথ্য পত্র

আমি সুমাইয়া নূর, বাংলাদেশ হেলথ প্রফেশন্স ইনস্টিটিউট (বিএইচপিআই) এর ছাত্রী যা পক্ষাঘাতগ্রস্থদের পুনর্বাসন কেন্দ্র (সিআরপি) এর একটি শিক্ষা প্রতিষ্ঠান। আমি বি.এস.সি ইন অকুপেশনাল ঘেরাপি বিভাগের ৪র্থ বর্ষে অধ্যয়নরত আছি। এই কোর্সের অংশ হিসাবে চূড়ান্ত বর্ষে আবশ্যকভাবে একটি গবেষণা কর্ম সম্পন্ন করতে হয়। আমি আপনাকে এই গবেষণায় অংশগ্রহন করার জন্য আমন্ত্রন জানাচ্ছি। গবেষণার বিষয় হচ্ছে মেরুরজ্জু আঘাত প্রাপ্ত প্যারাপিজিয়াদের সমাজে দৈনন্দিন জীবনযাত্রার উপকরণ কার্যক্রমের কর্মক্ষমতার অভিজ্ঞতা জানা সি.আর.পি থেকে পুনর্বাসন পরিষেবা নেয়ার পর "। এই গবেষণার লক্ষ্য হলো মেরুরজ্জু আঘাত প্রাপ্ত প্যারাগ্লিজিয়াদের সমাজে দৈনন্দিন জীবনযাত্রার উপকরণ কার্যক্রমের আত্মনির্ভরশীলতা অভিজ্ঞতা জানা মূলত এই গবেষণার উদ্দেশ্য যেমন মোবাইল ফোনের ব্যবহার, বাজার করা, খাবার তৈরি করা, গৃহস্থালির কাজ, কাপড় চোপর পরিষ্কার করা, যানবাহনে চলাচল, ওষুধ প্রস্তুতি এবং সরাসরি গ্রহণ করা,আর্থিক লেনদেন পরিচালনা করা।

এই গবেষণায় অংশগ্রহন সম্পূর্ণ আপনার ইচ্ছাকৃত। আপনি যে কোন সময় আপনার অংশগ্রহণ প্রত্যাহার করতে পারেন গবেষণায় অংশগ্রহণের জন্য কোন কিছু প্রদানের (আর্থিক) ব্যবস্থা নাই। আপনি এই গবেষণা থেকে সরাসরি উপকৃত নাও হতে পারেন। তবে গবেষণা থেকে প্রাপ্ত ফলাফল কর্তৃপক্ষকে মেরুরজ্জুতে আঘাত প্রাপ্তদের পুনর্বাসন চিকিৎসা সেবা সংক্রান্তসমস্যার সেবা প্রদানে সহায়ক হবে।

গবেষণার সাথে সম্পর্কিত কিছু নিজেস্ব কিছু প্রশ্ন নিয়ে আপনার একটি সাক্ষাৎকার নেয়া হবে যা অডিও টেপ দ্বারা সংরক্ষন করা হবে। আপনার কাছ থেকে প্রাপ্ত তথ্য গোপনীয়তার সাথে রাখা হবে ।শুধুমাত্র গবেষক এবং তার তত্ত্বাবধায়ক তথ্য গুলো ব্যবহার করতে পারবেন। আপনার পরিচয় গবেষণার কোথাও প্রকাশ করা হবে না। গবেষণা সংক্রান্ত আপনার যদি কোনরূপ প্রশ্ন থাকে তাহলে আমাকে দ্বিধাহীনভাবে জিজ্ঞাসা করতে পারেন। গবেষণা বিষয়ক সকল প্রশ্নের উত্তর দেবার জন্য আমি সচেষ্ট থাকবো।

সুমাইয়া নূর

বি.এস.সি ইন ইন অকুপেশনাল থেরাপি বিভাগ, ৪র্থ বর্ষ বাংলাদেশ হেলথ প্রফেশন ইনস্টিটিউট (বিএইচপিআই) সিআরপি, চাপাইন, সাভার, ঢাকা-১৩৪৩।

সম্মতি পত্র

আমি.....(অংশগ্রহণকারীর নাম), উপরোক্ত বিবৃতিটি পড়েছি এবং গবেষণায় আমার অংশগ্রহণের প্রকৃতি বুঝতে পেরেছি। আমি অবগত যে, সাক্ষাৎকারের সকল তথ্য যেগুলো গবেষণার কাজে ব্যবহৃত হবে সেগুলো গোপনীয়তার সাথে নিরাপদ স্থানে রাখা হবে। শুধুমাত্র গবেষক ও তত্ত্বাবধায়ক এ তথ্যগুলোর প্রবেশাধিকার পাবে এবং কারো নাম ও ঠিকানা কোথাও না ছাপিয়ে এ তথ্যগুলো প্রকাশিত হবে। আমি আরও অবগত যে, আমি গবেষণার এক মাসের মধ্যে আমার অংশগ্রহণ প্রত্যাহার করতে পারব। এ জন্য আমি কারো কাছে জবাবদিহি ও ক্ষতিপূরণ দিতে বাধ্য নই। আমি উপরোক্ত সকল তথ্যগুলো সম্পর্কে জানি এবং এই গবেষণার একজন অংশগ্রহণকারী হতে রাজী আছি।

অংশগ্রহণকারীর স্বাক্ষর.....

তারিখ.....

তথ্যগ্রহণকারীর স্বাক্ষর.....

তারিখ.....

গবেষকের সাথে যোগাযোগের ঠিকানাঃ

সুমাইয়া নূর

মোবাইল নাম্বার:০১৭৪২০৩৩৫৫৪

ই-মেইল: sumayanoor24@gmail.com

প্রত্যাহার পত্র

আমি.....(অংশগ্রহণকারীর নাম), উপরোক্ত বিবৃতিটি পড়েছি এবং গবেষণায় আমার অংশগ্রহণের প্রকৃতি বুঝতে পেরেছি। আমি অবগত যে, সাক্ষাৎকারের সকল তথ্য যেগুলো গবেষণার কাজে ব্যবহৃত হবে সেগুলো গোপনীয়তার সাথে নিরাপদ স্থানে রাখা হবে। শুধুমাত্র গবেষক ও তত্ত্বাবধায়ক এ তথ্যগুলোর প্রবেশাধিকার পাবে এবং কারো নাম ও ঠিকানা কোথাও না ছাপিয়ে এ তথ্যগুলো প্রকাশিত হবে। আমি আরও অবগত যে, আমি গবেষণার এক মাসের মধ্যে আমার অংশগ্রহণ প্রত্যাহার করতে পারব। এ জন্য আমি কারো কাছে জবাবদিহি ও ক্ষতিপূরণ দিতে বাধ্য নই। আমি উপরোক্ত সকল তথ্যগুলো সম্পর্কে জানি এবং এই গবেষণা থেকে নিজেকে প্রত্যহার করতেছি ।

অংশগ্রহণকারীর স্বাক্ষর……..

তারিখ.....

প্রত্যহারের কারণ……..

তথ্যগ্রহণকারীর স্বাক্ষর……..

তারিখ……

Appendix C: Interview Guide

Demographic data and self-developed interview guide (English)

Sociodemographic data

Name:

Gender: Male: ☐ Female: ☐

Age: ☐

Marital status:

Married: ☐ Unmarried: ☐ **Religion**: ☐

Family status:

Family members: ☐

Number of children: ☐

Son: ☐ Daughter: ☐

Living status:

Rural**:** ☐ Semi -Urban: ☐ Urban: ☐

Occupational status: ☐

Educational status: ☐

Injury level: ☐

Time since injury: ☐

Assistive device: ☐

Discharge: ☐

Financial status: ☐

Sociodemographic data (Bangla)

নামঃ

লিঙ্গঃ পুরুষঃ ☐ মহিলাঃ ☐

বয়সঃ ☐

বৈবাহিক অবস্থাঃ

বিবাহিতঃ ☐ অবিবাহিতঃ ☐ **ধর্মঃ** ☐

পরিবারের সদস্যঃ ☐

সন্তান সংখ্যাঃ ☐

ছেলেঃ ☐ মেয়েঃ ☐

বসবাস এলাকা:

গ্রামঃ ☐ উপ শহরঃ ☐ শহরঃ ☐

পেশাঃ ☐

শিক্ষাগত যোগ্যতাঃ ☐

ইনজুরি লেভেলঃ ☐

ইনজুরি তারিখঃ ☐

সহায়ক উপকরনঃ ☐

ডিসচার্জ তারিখঃ ☐

আথির্ক অবস্থাঃ ☐

Self-developed semi-structure interview guide

Questions with objectives

Objectives	Questions
	1)What types of works do you perform in your house after taking service from CRP?
Health management and maintenance	2)Do you have any exercise in everyday which is learned from CRP? If you do, how do you do it? –What do you think is the appropriate place to exercise? 3)Is the exercise's place facilities suitable for your accessibility? 4)Do you take any medicine and prepared by yourself? If you do, how do you take it? –How do you prepare it before taking?
Home establishment and management	5)Do you obtaining and maintaining your household chores by yourself (e. g: cleaning and preparing bed. room, yard) -Are house cleaning items (broom, mob) suitable for you? 6)Do you wash and iron of your clothes and your family? If you do how you do? 7)Is the cleaning and washing environment is suitable for you?
Shopping	8)Do you market for yourself and your family? If you do, how do you do? 9)Do you buy all the necessary things from one place (supermarket) or different shops? 10) Are the shop's facilities being suitable for your accessibility? 11)How do people aspect you when you go to the market? How do you feel then?
Meal preparation and clean up	12)Do you cook or help in cooking. If you do, how do you do it? 13)What kind of preparation do you take before cooking? And how do you cook? –Dose anyone help you while cooking? And what kind of help does it do? 14)Do you serve food? If you do, how you do it? 15)Is your kitchen environment suitable for you? –Are the cooking items (spices jar, utensil, knife, pot etc) with in your reach?

Community mobility	16)How do you go to outside for your work? 17)Do you use public transport? If you do, how do you use it? 18)Are the public transports facilities is suitable for your accessibility? 19)How are the aspect of people in the public transports about you? How do you feel then?
Financial management	20)Do you have any financial transactions in the bank? If you have, how do you do? 21)How do you use agents (Baksh, rocket, nogod, etc) to deposit money for paying various bills (electricity, gas etc). 22)Is the accessibility of bank and boot suitable for you?
Communication management	23)Do you use the telephone /mobile for communication? Can you use it appropriately? –how do you recharge? –how do you charge the phone?
	24)Do you have any recommendation for your family and the people who are like you?

Self-developed interview guide (Bangla)

১) আপনি সি আর পি তে সেবা নিয়ে আসার পর বাড়িতে নিত্যদিন কি কি কাজ করেন?

২) আপনি কি নিয়মিত শারীরিক ব্যায়াম করেন? করলে তা কিভাবে করেন?

- ব্যায়াম করার জন্য উপযুক্ত জায়গা কোনটি মনে করেন?

৩)ব্যায়াম করার উপযুক্ত জায়গাটি কি আপনার প্রবেশগম্যতার জন্য উপযুক্ত কিনা ?

৪) আপনি কি কোনো ঔষধ গ্রহন করেন? করলে তা নিজে করতে পারেন কি?

- প্রস্তুত করা খাওয়ার আগে

৫) আপনি কি আপনার ঘর বাড়ীর কাজ গুলি নিজে করতে পারেন (যেমন, বিছানা,ঘর, উঠান) পরিস্কার করা বা প্রস্তুত করা?

-ঘর পরিষ্কার করার জিনিস (ঝাড়ু, মব) আপনার জন্য উপযুক্ত কিনা?

৬)আপনি কি আপনার নিজের এবং আপনার পরিবারের সদস্যদের জন্য কাপড় চোপড় পরিষ্কার করেন?করলে তা কিভাবে করেন?

৭)কাপড় পরিষ্কার ও ইস্ত্রি করার পরিবেশটি আপনার জন্য উপযুক্ত কিনা?

৮)আপনি কি আপনার ও আপনার পরিবারের জন্য নিজে বাজার করতে পারেন? করলে তা কিভাবে করেন?

৯)প্রয়োজনীয় সব জিনিস কি আপনি একজায়গা থেকে কিনেন, না বিভিন্ন জায়গা থেকে কিনেন?

১০)বাজানের দোকান গুলির প্রবেশগম্যতা কি আপনার জন্য উপযুক্ত কি না?

১১)বাজারে গেলে আপনার প্রতি লোকজনের দৃষ্টিভঙ্গি কেমন? এবং তখন আপনার কেমন লাগে?

১২) আপনি কি রান্না করেন বা রান্নার কাজে সাহায্য করেন, করলে তা কিভাবে করেন?

১৩) রান্নার আগে আপনি কি ধরনের প্রস্তুতি গ্রহন করেন? এবং কিভাবে রান্না করেন?

-রান্নার সময় আপনাকে কি কেউ সাহায্য করে?করলে তা কি ধরনের সাহায্য করে?

১৪) আপনি কি খাবার পরিবেশন করেন ? করলে তা কিভাবে করেন?

১৫) আপনার রান্না ঘরের পরিবেশ আপনার জন্য উপযুক্ত কি না?

- রান্নার সব ধরনের উপকরন আপনার নাগালের মধ্যে থাকে কি না(বাসন,মসলার কৌটা, ছুরি, পাত্র ইত্যাদি)?

১৬) আপনি কোনো কাজে বাড়ীর বাইরে কিভাবে যান?

১৭)আপনি কি গণপরিবহন ব্যবহার করেন? করলে তা কিভাবে করেন?

১৮)গণপরিবহন গুলি কি আপনার প্রবেশগম্যতার জন্য উপযুক্ত কি না?

১৯)গনপরিবহনে অনান্য যাত্রীদের দৃষ্টিভঙ্গি কেমন আপনার প্রতি? তখন আপনার কেমন লাগে?

২০) আপনি কি ব্যাংকে কোনো আর্থিক লেনদেন করেন? করলে তা কিভাবে করেন?

২১)আপনি কি টাকা আদান প্রদানের জন্য এজেন্ট (বিকাশ, রকেট, নগদ ইত্যদি) ব্যবহার করেন, বিভিন্ন বিল(বিদ্যুৎ গ্যাস) ইত্যাদি কাজ গুলি কিভাবে করেন ?

২২) ব্যাংক এবং বুত গুলির প্রবেশগম্যতা আপনার জন্য উপযুক্ত কিনা?

২৩) আপনি কি যোগাযোগ এর জন্য মোবাইল /টেলিফোন ব্যবহার করেন? করলে সঠিক ভাবে তা ব্যবহার করতে পারেন কি ?

- মোবাইল রিচার্জ কিভাবে করেন?

- মোবাইল চার্জ কিভাবে দেন?

২৪)আর কোনো সুপারিশ আছে কি আপনার পরিবার প্রতি বা আপনার মতো আর যারা আছে?

Appendix D: Field Note

Participant one: Kabir

Kabir was very cooperative and conducting interviews properly while working his garden. He could not control tears talking about people's negligence. He lived in a grounded house with helping hand. There was a ramp from yard to veranda. The kitchen and washroom were in attached to living room. But the tube well was not appropriate for him.

Participant two: Nobel

Nobel was helpful but little shy for his current health condition during interview. He lives in tin shed house with his niece and sister- in- law. Accessible kitchen and wash room were attaches in the residence. However, there was no ramp to get down from house instead of stair. The entrance of house was not suitable for wheelchair.

Participant three: Alim

Alim initially exhibited a lack of cooperation and seemed irritated. He was not so much cooperative and feeling irritated at first time. He lived in a congested room. His main home entrance is quite impossible to move with wheelchair. His yard was uneven. His washroom and kitchen were separated from his living room. The kitchen was not appropriate for him to cook as well as washing space. He remained with his wife and five-year-old son.

Participant four: Robin

Robin was helpful. He lived a rental tin shed rent house because his previous home was on third floor and there was no lift. The kitchen and wash room were accessible as well as home environment. He stayed with his wife in the new home. There was a ramp to get down from veranda to yard.

Participant five: Jakir

Jakir had pressure sores, which caused him to appear worried. That made him sad during interview session. He was sad about that. When he was taking about his family responsibility, he was unable to contain his tears. His both legs were swelled and he indicated pressure sore lift side hip portion. He lived in a mud house with his family. The road was too narrow that he did not out. The road next to the house was very risky to move with wheelchair due to its extreme unevenness and abundance of holes. There was a ramp made of muddy and that was damaged as a result of rain. The kitchen was in open place and the washroom was very poor structure and not accessible with wheelchair.

Participant six: Mubin

During the interview, Mubin was very cooperative. He lived in a tin shed. The kitchen room was not appropriate but was accessible. To get down from veranda, there was a ramp. There was not appropriate way to go outside and main road. He lived with his wife and 12 years old daughter.

Participant seven: Sofiya

Sofia was very cooperative in interviewing session. She lived with his family on fourth floor in a rent house. The living was congested not enough space to move with wheelchair. The kitchen and washroom were not wheelchair accessible. She lived with his husband,10 years daughter, daughter in law and her son.

Participant eight: Rita

She was very assertive and jolly minded. She answered every question with confident. The living room, kitchen room, washroom everything was appropriate for her with wheelchair accessibility. The entrance of house and the house next to road was appropriate to move with wheelchair. She lived with her father, mother and younger brother.

Supervision Schedule 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: Experience of performing Instrumental Activities of Daily Living at community of adults with paraplegia following rehabilitation.

Name of student: Sumaya Noor

Name and designation of thesis supervisor: Md. Julker Nayan, Associate professor, Department of Occupational Therapy

Appointment No	Date	Place	Topic of discussion	Duration (Minutes/ Hours)	Comments of student	Student's signature	Thesis supervisor signature
1	22.08.22		• Research title • Aim & objectives	45 minute	feedback of aim & objective	Sumaya noor	
2	24.08.22		• Background, significance • Methodology	1 hour	feedback of background, significance & methodology	Sumaya noor	
3	02.10.22		self develop question	7 minute	feed back of self develop question	Sumaya noor	

4	13.10.22		Research conduct aplication, consent form, withdrawl fonm,				
5	~~07.12.22~~		~~Analysis~~	~~28 min~~	~~All good~~ Informative	Sumaya noor	
6	07.12.22	BHPI Office Building	Data Analysis	28 min	Guiddins for Data Analysis and feed baek	Sumaya noor	Ayma 07.12.22
7	20.12.22	BHPI Office bulding	Data Analysis	35 min	Feed baek of Theme and sub them (Analysis) Guidlines for result	Sumaya noor	Ayma 20.12.22
8	15.04.23	BHPI Office buding	Result. Methods	~~15 min~~ 1hr 50 min	Feed baek result methods	Sumaya noor	Ayma
9	16.01.23	BHPI	Introduction, Methodology feedback	45 min	Feed baeks and guidelines	Sumaya noor	16.01.23
10	1.03.23	BHPI	Research result feedback	30 mins	Got clear udenstanding result	Sumaya noor	Su. Noor
11	14.05.23	BH PI office Building	Resut.	35 min	Feedbaek and guidelines	Sumaya noor	Ayma
12	31.05.23	BHPI	Research final draft feed baek	30 min	Get connection of matting an downi mistake	Sumaya noor	
13	31.05.23	BHPI	Research finaldraft feed baek	30 min	Get connection of formatting	Sumaya noor	Su. Noor
14							