

Coping Strategies of Primary Family Caregivers of the People with Spinal Cord Injury: A Cross-Sectional Study



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

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Statement of Authorship

This thesis includes no information from my previous work for any other degree or seminar, either in whole or in part. No other person's work has been used without due acknowledgement in the main text of the thesis. This thesis has not been submitted for the award of any other degree in any other tertiary institution. The ethical issue of the study has been strictly considered and protected. In case of dissemination of the findings of this project for future publication, the research supervisor will be highly concerned, and it will be duly acknowledged as an undergraduate thesis.

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Dedication

The research paper is dedicated to our Creator, Almighty Allah who gave protection, knowledge, and strength to complete this study. I also dedicate it to my parents and family members who gave never ending support and inspiration. The researcher would like to dedicate it to the teachers who were behind this study and helped in making it possible by giving me the guidance to complete the study. Finally, it is dedicated to the Institution who gives opportunity to the students to test, nurture their skills and cooperate to build the study.

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List of Abbreviations

BHPI	Bangladesh Health Professions Institute
CAPI	Computer Assisted Personal Interview
CBR	Community Based Rehabilitation
CRP	Centre for the Rehabilitation of the Paralysed
F-COPES	Family Crisis Oriented Personal Evaluation Scales
ICU	Intensive Care Unit
ITC	International Test Commission
IRB	Institutional Review Board
OT	Occupational Therapy
PAPI	Paper And Pencil Interview
SCI	Spinal Cord Injury
SD	Standard Deviation
SPSS	Statistical Package of Social Science
TSCI	Traumatic Spinal Cord Injury
UK	United Kingdom
USA	United States of America
WHO	World Health Organization
WMA	World Medical Association

Abstract

Background: Spinal cord injury (SCI) affects many aspects of human functioning causing the person to require care from family members. Caregiving for such chronic conditions has its good and bad effects. Evidence suggests identifying the way that caregivers cope, the effects of it can be assessed. Coping is a person's cognitive and behavioral efforts in response to stressors that direct how those stressors will affect physical and emotional well-being. With the increasing need of caregiving worldwide the way caregivers cope should be studied in a nation like ours that hasn't yet developed long-term care policies and provisions for care.

Aim: To investigate the coping strategies used by the primary family caregiver of people with SCI in both Rehabilitation center and in the Community.

Methods: The study is done following quantitative cross-sectional design. Data was collected from 134 participants by face-to-face survey using the F-COPES (Family Crisis Oriented Personal Evaluation Scales). Descriptive analysis was done using SPSS v.20. The mean and SD of each subscale score and total score of the F-COPES were calculated to determine and compare the coping strategies that were used by family primary caregivers of a person with SCI among the two groups: rehabilitation center and community. Further Mann-Whitney and Kruskal-Wallis test was done to find out the association between the total F-COPES score of the two groups and also the association between coping and socio-demographic factors.

Result: Findings showed in two areas, rehabilitation center and community the female participants were 73.1% and 76.1% and male participants were 26.9% and 23.9%. The

mean of overall scale revealed participants used coping on a moderate level and mean of the subscales revealed in both areas, reframing was most used coping strategy. Rehabilitation center participants varied from community by using family support in fourth and passive appraisal was the least used whereas in community family support was the least used. Except for the coping strategy mobilizing family support ($p= 0.000$), no statistically significant differences were found between F-COPES total and subscales between rehabilitation center and community. In terms of association between coping and socio-demographic factor only in gender there's a significant difference in mean ranks of rehabilitation center but not in community. However, there were no significant differences in mean ranks of other factors (e.g. age, duration of caregiving, level of education etc.) among both groups. Meaning that coping did not differ according to other factors but may differ due to gender of the caregivers.

Conclusion: This study finds and compares the coping strategies that are used among the family primary caregivers of person with SCI in a rehabilitation center and community. The study contributes to the field of rehabilitation science by guiding therapists or rehabilitation service provider in Bangladesh on how to incorporate families into culturally appropriate and competent interventions.

Keywords: Coping, Spinal Cord Injury (SCI), Family caregiver, Rehabilitation.

CHAPTER I: Introduction

1.1 Background

Spinal cord injury (SCI) is a great calamity upon the person and the person's family (Dijkers, n.d.) causing the person to need continuous supervision in day-to-day living, many impacted people receive familial support who adopt the role of caregiver and become the protagonists of care (Gajraj-Singh, 2011; Post et al., 2005; Zanini et al., 2022). In case of spinal cord injury (SCI), the condition affects human functioning (Bickenbach et al., 2013), including body functions and structures (Brinkhof et al., 2016; Sezer et al., 2015; Sweis & Biller, 2017), activities and participation in society (Chang et al., 2018; Chhabra & Batra, 2016) so the support of family caregivers is particularly valuable. Both globally and locally trauma is the most common cause of SCI (Patek & Stewart, 2023). The incidence of TSCI worldwide range from 3.3 to 195.4 cases per million with male predominance and affecting the middle and low socio-economic societies more often (Jazayeri et al., 2023; Quadir et al., 2017).

In healthcare provision the informal caregivers form a fundamental aspect (Ng & Indran, 2021). In Western countries like USA the prevalence of caregiving for an adult or child with special needs is reported to be 18.2% to 21.3% and in Europe informal caregivers are 10% up to 25% of the total population (Shih2020, n.d; Zigante, 2018). In Asian countries such as Malaysia has 5.7% of adult population as informal caregiver and Singapore has 8.1% prevalence of informal caregiver (Kong et al., 2021; *Statistics Singapore Newsletter*, 2011).

In the field of SCI, family members, who look after the SCI patient in the majority of cases also falls victim to the event beyond its control. Researchers consistently report elevated levels of relationship and financial hardship, stress, depression, anxiety, and a general decline in health and quality of life (Baker et al., 2017; Fekete et al., 2017; Lynch & Cahalan, 2017; Maitan et al., 2018). However, providing care can also have advantageous outcomes. Research indicates that providing care can lead to a rise in self-efficacy, facilitate the acquisition of new abilities, create a sense of fulfillment and reward, and improve relationships with the care recipient (Li & Loke, 2013; Morrison et al., 2014; Schulz & Sherwood, 2008). Finding the way caregivers cope, the implications of providing care might potentially be clarified. Studies in different fields have shown that adjustment in caregivers are predicted by significant coping strategies. For example, in case of dementia, caregivers higher self-reported health and life satisfaction were associated with increased usage of coping mechanisms (Haley et al., 1987) and in caregivers of people with Parkinson disease, higher coping strategies resulted in enhanced quality of life and enhanced psychological adjustment (Navarta-Sánchez et al., 2016). Similarly, among caregivers of people affected by advanced cancer thanks to coping strategies psychological wellbeing was enhanced (Walshe et al., 2017). Support should be provided to resolve all doubts as well as to learn knowledge and skills needed to cope with a new and potentially more stressful life.

A person's cognitive and behavioral responses to stressors that control how those stressors will influence their physical and emotional well-being are referred to as coping (Lazarus & Folkman, 1984). Coping strategies can depend on various factors, one of which

is sociodemographic characteristics (Asturias et al., 2021; Bottaro & Faraci, 2022; Lembas et al., 2017).

The study focuses on family primary caregivers for several reasons. First off, the experiences of family caregivers in Bangladesh caring for people with disability are not well studied and it is vital to encourage academic research and effective intervention (Ahsan, 2023). Second, Asian nations are particularly unfamiliar with the problem associated with caring in contrast to Western states that have long developed long-term care policies and provisions for care (Zhang & Jean Yeung, 2012). Third, providing care to family members does not always come without costs. Family caregivers appear to have worse health and psychological wellness, according to a study comparing them to the general population (Davies & Young, 2017). Fourth, unlike other developing countries, Bangladesh does not prioritize medical rehabilitation or disability management; instead, the focus is on primary healthcare services, particularly acute care (Uddin et al., 2019). Also, literature hasn't done a good job of addressing the unique needs of family members in coping with the abrupt trauma of a spinal cord injury or the long-term effects of rehabilitation in our nation. It's rarely acknowledged that family members may also need to use unique coping strategies to manage both the acute and chronic stages of this illness (Atwood, 2017; Reinhard et al., 2019; Roth et al., 2015). In many ways, the adaptive changes of such families are comparably equal to the changes required of the patient (James Litman, 1966).

This study provides a baseline for family caregivers' coping strategies based on their sociodemographic characteristics. Given that the study is comparative allows us to identify how the family caregiver cope when staying at a rehabilitation center versus when

they are living in the community. Finally, this study can be used to establish plans of care and intervention that would emphasize skills and coping strategies for them to better cope and adapt, minimize family members' burden, enabling them to provide better care and, as a result, indirectly decreasing family members' institutionalization (Fadili et al., 2016; Guedes & Pereira, 2013). In light of this, the community should provide care and support to the patient as well as their family (Ma et al., 2014).

1.2 Justification of the study

The coping strategies of the primary family caregivers of people with SCI should be studied in a much broader sense for getting a clear understanding and insight on how they deal with the adverse situation along with the behavioral and emotional changes taking place. As we know, most of the time the family members are the caregivers. Research in this area will help family members to identify their coping strategies to prevent burnout and maintain their own health and quality of life. Moreover, a family's ability to adapt and cope with the situation influences the quality of care provided which plays a crucial role on patient's recovery and effective treatment outcome.

Rehabilitation professionals often limit their attention to patients with SCI, ignoring the patient's family members. Such unequal and single-focus intervention may be inadequate and considering the concept of holistic care to be followed by us as occupational therapists, we cannot separate the needs of patient from those of the patients' families. The coping strategies identified among family members in this study will help to establish plans of treatment which will include use of active coping strategies, better adjustment, manipulating patient's attributional belief, perceiving social support and coping strategies endorsement which will also indicate rehabilitation professionals to adopt a multi focused

intervention strategy to ensure the best therapeutic results.

This study will have potential benefits for our country as well, as understanding the unique challenges faced by families of person with SCI within cultural and healthcare context will lead to development of targeted support programs and services to assist caregivers, better access to healthcare services and rehabilitation programs in Bangladesh, reduce emotional/financial burden, raise awareness about the challenges they face ultimately leading to a more inclusive and supportive community.

1.3 Operational Definition

1.3.1 Coping Strategies: Coping strategies refer to how people deal with a certain problem (Murphy, 1974; Pearlin & Schooler, 1978; Zeitlin, 1980).

1.3.2 Family caregiver: A family caregiver could be a son, a daughter, a parent, a spouse, or another member of the family or acquaintance. In addition to being with the patients, the caregiver makes time to give them the attention they need (Factors et al., 1999; Pinquart & Sörensen, 2003).

1.3.3 Primary caregiver: Those who are in charge of giving care to someone who is unable to take care of themselves are referred to as primary caregivers (Yan, 2019).

1.3.4 Spinal Cord Injury: Spinal cord injury can simply be defined as damage to the spinal cord which is usually caused by several factors, such as, disease, degeneration, or trauma (“World Health Organization: WHO,” 2013).

1.4 Aim of the study

To investigate the coping strategies used by the primary family caregivers of people with SCI in both Rehabilitation center and in the Community.

CHAPTER II: Literature Review

In this section, information is provided from existing literature on different coping strategies, family caregiver and relation of coping strategies with some socio-demographic factors such as age, gender, education level, duration of caregiving, relationship with person with SCI and financial condition.

According to Lazarus and Folkman's (1984) coping is classified as problem-focused and emotion-focused coping strategies. Problem-focused coping involves using techniques to change or manage it for removing the perceived stressor by increasing control over it. It includes making decisions, active planning, resolving interpersonal conflicts and learning more about the stressor. Emotion-focused coping, on the other hand, focuses on behavioral and cognitive strategies for controlling and overcoming anxious emotional responses to stresses (Lazarus & Folkman, 1984). Emotion-focused coping is further subdivided into avoidant processes, which include substance abuse, self-distraction, and denial to minimize the impact of negative emotional responses and active coping strategies, which alter a negative emotional response e.g., acceptance, positive reframing, or religion (Holahan and Moos, 1987; Sheridan & Radmacher, 1992).

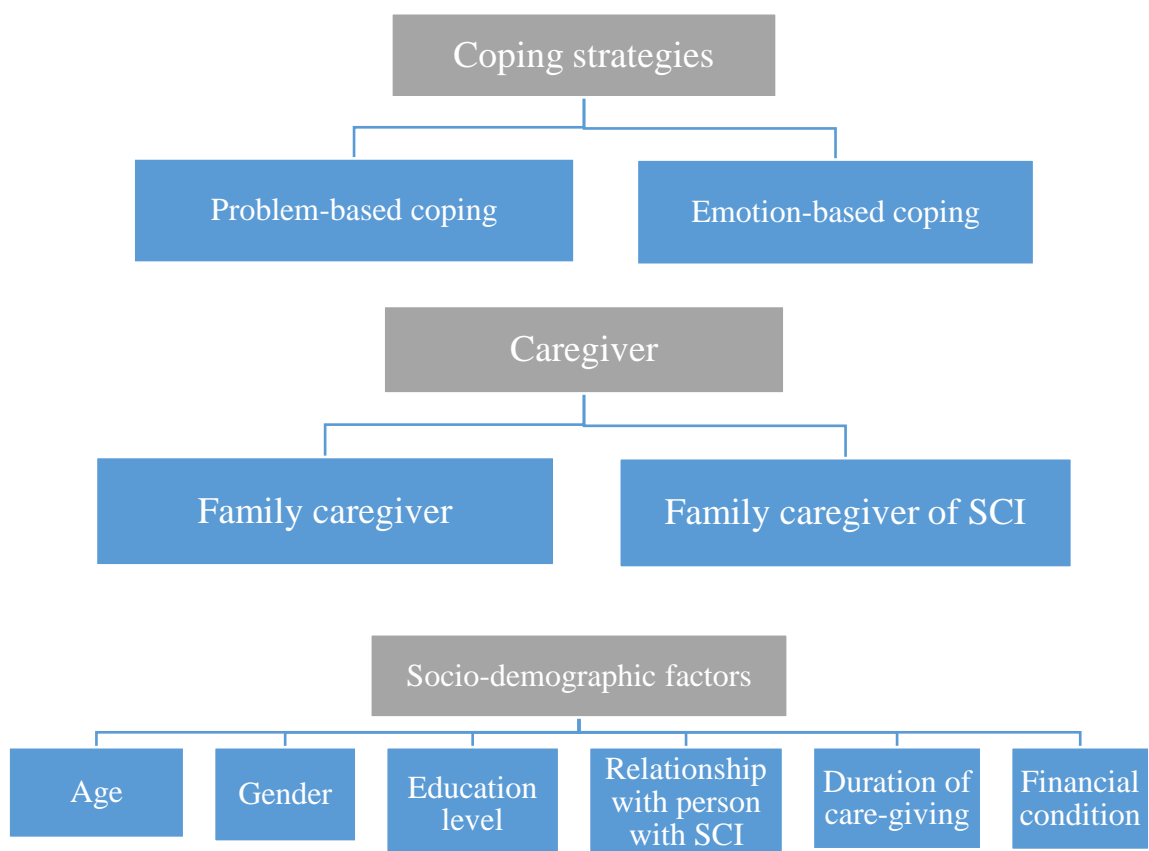


Figure 2.1: Overview of literature review findings

2.1 Coping strategies

2.1.1 Emotion-focused Coping:

A descriptive study of families of 120 patients who were hospitalized in ICU in University Hospital in Turkey. They found similar to other studies that families facing financial difficulties and not receiving assistance from others primarily used the submissive and helpless/self-blaming coping mechanism which are emotion-focused strategies (Acaroğlu et al., 2008; Alvarez & Kirby, 2006; Juczyński & Adamiak, 2005). In another descriptive study in two community hospitals' critical care units within first 48-96hrs of admission in USA the aim was to examine coping and anxiety levels of the family members of the patient. The result was anxiety level was adversely correlated with the coping subscale

passive appraisal among 75 participants using the coping instrument F-COPES (Reider, 1994). Using the same instrument another cross-sectional study found results opposite to the previous study where reframing (a emotion-focused coping style) was most used and passive appraisal was least used. It had 133 participants who were the family members of patients admitted in 2 ICUs within 24hrs of regional general hospital in Hongkong (Chui et al., 2007). A study in Iran with the aim of identifying the coping mechanisms used by family caregivers of schizophrenia patients had 225 participants using descriptive correlational cross-sectional method also found most family members used emotion-focused strategies which was avoidance (Rahmani et al., 2019).

2.1.2 Problem-focused coping:

Most participants among 40 spouses had experienced stress throughout six months of providing care, they applied both problem- and emotion-focused techniques. It was a cross-sectional study drawing participants from regional hospitals, rehabilitation centers, voluntary organizations, and self-help groups in Honk Kong. The aim was to look at the stressors and coping mechanisms used by spouses of SCI patients (Chan, 2000). A study assessed the caregivers coping strategies and sociodemographic factors of chronic hemodialysis patients of a hospital in Saudi Arabia. The result was caregivers used planful problem solving, self-control and positive reappraisal. Furthermore, they found the least used coping strategies were confrontive and escape-avoidance (Fadili et al., 2016). On the other hand, a study of caregivers of dependent family members receiving care from two health centers of North of Portugal, reported using more of alternative perceptions of the situation and solving the problem or dealing with the situation (Guedes & Pereira, 2013). Similarly at a psychiatric hospital of Sao Paulo, family members' coping mechanisms were

the focus of the descriptive study that aimed to relate the coping mechanisms to the patient's clinical characteristics and family member sociodemographic characteristics. The results were social support and problem solving coping strategies most often used by family members (Pompeo et al., 2016).

2.2 Caregiver

2.2.1 Family caregiver

Family or informal caregiving is a demanding and all-consuming task that often negatively impacts the financial, emotional, and social well-being of the caregiver (Eifert et al., 2015). While family members are extremely important in providing patients with care and assistance with long-term diseases, they are also a great source of support for them (Chadda, 2014). Roughly 90% of people who look after someone with a chronic illness are their family members (Corcoran, 1994; Ehrlich et al., 1992). Usually, the caregiver is a woman from a variety of socioeconomic backgrounds., either the patient's wife or daughter, between the ages of 29 years and 68 years. For months or even decades, she has been providing care, and she usually lives with the patient (Zarit et al., 1987). In a study conducted in Brazil, findings where caregivers devote an average of 11.3 hours per day in providing care, demonstrating an almost total dedication. In addition, they are accountable for household duties and provide care for other dependent family members. Caregivers for hemodialysis patients on average spent eight hours a day on caregiving. Despite the fact that majority of caregivers (73.3%) have jobs outside, some of them (26.7%) were housewives or retired and did not engage in any type of outside employment (Belasco & Sesso, 2002). In comparison to the general population, caregivers are more likely to have psychopathology than physical illness, visit doctors more frequently, and report being in

worse health (Belasco & Sesso, 2002).

2.2.2 Family caregiver of SCI

Unlike studies evaluating elder care (Russo et al., 1995; Zarit et al., 1987), a study of caregivers found that in addition to spouses (26.6%) and mothers (18.3%) the sisters (23.4%) also provided care for individuals with SCI paraplegia. It could be explained by the fact that the mean age of paraplegics is often younger (32.9 years) (Blanes et al., 2007). These findings are comparable to a study of individuals with SCI, where wives are highlighted as the primary caregivers while other family members are mentioned less frequently. Typically, the wife bears most of the caregiving duties. Prior research indicates that caregivers' physical difficulties often stem from psychosomatic issues (Karlin, 1995; Schulz & Sherwood, 2008; Ünalán et al., 2001). Most papers in this subject all convey the same message about how SCI negatively affects close family members, such as spouses and/or primary caregivers (Alfano et al., 1994; Feigin, 1994; Gerhart, 1991; Kreuter, 2000; North, 1999; Weitzenkamp et al., 1997). Many studies have been done on the effects of SCI (not severity) on families (Alfano et al., 1994; Feigin, 1994; Killen, 1990; Kreuter, 2000; Lapham-Randlov, 1994; North, 1999; Sherrard, 1995; Sullivan, 1990; Weitzenkamp et al., 1997;). According to reports, the effects of SCI may cause significant adjustments to family members' roles (North, 1999). When it comes to the stability of the marriage, SCI makes the patient's spouse feel vulnerable. Additionally, spouses have stated that because of SCI, they have a greater sense of dependency and a bigger fear of being alone (Feigin, 1994; North, 1999; Weitzenkamp et al., 1997). It has been observed that the wives of SCI patients—who are also their caregivers—face a great deal of stress in relation to their finances, mental health, marriage, and social contacts due to the condition (Chan et al.,

2000; Moore et al., 1991).

2.3 Socio-demographic factors

Coping strategies are seen to be associated with demographic characteristics such as age, gender, education level, financial condition, duration of caregiving and caregiver burden (Bottaro & Faraci, 2022; Lembas et al., 2017; Rahmani et al., 2019).

2.3.1 Age:

A study shows distancing and escape-avoidance were observed to be the two main coping mechanisms used by older and married spouses. Younger people with shorter term marriages were more problem-focused and had friends to help them (Chan, 2000). Conversely another study result where older are seen using more problem-focused strategies compared to young family caregivers (Rahmani et al., 2019). In a study of caregivers between the ages of 30-45, people over 45 tended to utilize confrontive coping strategies and take on greater responsibility than those under 30 (Fadili et al., 2016). However, significant differences were not found in coping strategies in terms of age, years of schooling or religion in another study (Pompeo et al., 2016).

2.3.2 Gender:

In an Iranian study evaluating coping mechanisms, family caregivers of schizophrenia patients primarily employed avoidance, compulsion, and resignation. Maladaptive coping mechanisms was employed by 54.22% of caregivers, whereas 45.78% employed adaptive ones. When it comes to problem-focused coping mechanisms, male caregivers were more likely to use them than female caregivers (Rahmani et al., 2019). Nevertheless, according to a different study, women are more likely than men to escape, avoid, and solve problems (Pompeo et al., 2016). In another study, only one coping method differed significantly by

gender, where men utilized distancing more frequently than women (Fadili et al., 2016). Other numerous studies have shown that women adopt more social support than men in coping with anxiety (Acaroğlu et al., 2008). In a study involving a significant number of female spouses of patient from an affiliated hospital of Nanchang University in China, males with higher levels of education were shown to employ active coping strategies more frequently than females. Despite the gender disparity in the study, it was possible to assess the health issues that arise from providing care for their patients (Ma et al., 2014).

2.3.3 Education level:

A higher level of education allows caregivers to use problem solving strategy more since they can obtain better positions, offer more resources, assistance, and compensation (Rahmani et al., 2019). Distancing and self-controlling was found to be associated with lower education level (Fadili et al., 2016). Similarly females caregivers with limited education used less active coping than males with high education (Ma et al., 2014).

2.3.4 Relationship with person with SCI:

A exploratory research reported after son/ daughter's traumatic spinal cord injury, mother's role were becoming more strained over time and the father and injured child struggled to communicate their desires for dominance and control (Atkins, 2005). Son/daughter employed self-control more than spouses, and the spouses was more likely than the others to seek help (Fadili et al., 2016). Parents are more likely than siblings, children, or other family members to use self-control strategies, social support, and positive reappraisal and family members with a partner do better in problem solving than those without a partner who turn to avoidance and escape as a coping mechanism. Families of patients who do not exhibit psychotic symptoms typically use problem solving strategies more frequently

(Pompeo et al., 2016). Other caregivers (in-laws, nephews, brothers) reported using more "dealing with the situation or solving the problem" and "alternative perceptions of the situation," while spouse and child caregivers demonstrated less usage of effective coping methods (Guedes & Pereira, 2013). Besides that, spouses of the SCI patient were also more likely to use negative coping strategies (Chan, 2000) and a study shows 26% of the men were divorced during the time of study who were married at the time of injury (El Ghatit & Hanson, 1975).

2.3.5 Duration of caregiving:

It is reported that caregivers' increased use of planful problem solving is caused by increased hours of care-giving (Fadili et al., 2016). Results indicated that coping strategies were associated with longer durations of care and lower levels of psychological morbidity and burden. A significant positive relationship was also established between coping strategies and length of caregiving (Guedes & Pereira, 2013).

2.3.6 Financial condition:

Financial problems can induce a lot of anxiety, that is experienced by 56.7% of the participants due to patient hospitalization in the ICU in Turkey. As the level of anxiety increased they used submissive and helpless coping styles (Acaroğlu et al., 2008). Family caregivers experience stress due to financial issues, which leads to the adoption of unhealthy coping mechanisms. Additionally, the chronic nature of mental illness increases the financial strain on caregivers (Rahmani et al., 2019). Families with four to seven minimum-wage earners utilize more positive reappraisal (Pompeo et al., 2016).

2.4 Key gaps of the study:

1. Many studies reviewed were conducted in countries: Turkey, Portugal of Europe continent, Brazil in South America continent and USA in North America. In Asia continent conducted studies were in Iran, Saudia Arabia, and China mainly less studies in the developing countries.
2. Literature review of articles published in English, not representing non-English speaking regions.
3. Studies have limited generalization due to homogeneous samples.
4. The idea that coping is static and trait-like is supported by the fact that family members' coping reactions are based on single time points.
5. Most are cross-sectional studies with limited depth and breadth of data.

CHAPTER III: Methods

3.1 Study Question, Aim, Objectives

3.1.1 Research Question

What are the coping strategies of primary family caregivers of the people with SCI, and the association among those in rehabilitation center and in the community?

3.1.2 Aim

To investigate the coping strategies used by the primary family caregivers of people with SCI in both Rehabilitation center and in the Community.

3.1.3 Objectives

- To find out the socio-demographic characteristics of primary family caregivers of people with SCI in Rehabilitation center and Community.
- To identify the coping strategies used by the primary family caregivers of people with SCI.
- To determine the association of coping strategies between the two groups.
- To determine the association between coping and socio-demographic factors of primary family caregiver of people with SCI.

3.2 Study Design

3.2.1 Study Method

Quantitative research method was used for this study. This method deals with numerical data or can be turned into numbers. Statistical technique was used for organizing, analyzing and interpreting the numerical data for this study.

3.2.2 Study Design

The study chose cross-sectional design as cross-sectional studies are observational studies in which data from a population is analyzed at a specific point in time. For instance, this design is frequently used to assess the frequency of health outcomes, comprehend health factors, and define characteristics of a population. They are usually affordable and simple to carry out (Wang & Cheng, 2020). So, as in case of this study, population (family primary caregiver of individual with SCI) within a defined time period is selected as like taking a snapshot and analyzing data to determine characteristics: the exposure (spinal cord injury) and outcome (coping strategies), the quantitative cross sectional study design is chosen to be the best suited.

3.3 Study Setting and Period

This study was conducted in Spinal Cord Injury Unit in the Centre for the Rehabilitation of the Paralyzed, and in the Community (Savar area) of person with spinal cord injury who took rehabilitation service from CRP, Savar.

The study period was from May'2023 to February'2024 and data collection period was from 1st December'2023 to 31st December'2023.

3.4 Study Participant

3.4.1 Study population:

The population in this study will be the primary family caregivers who have at least 1 month experience of taking care of the person with SCI and is admitted to CRP, Savar and now live in the community after taking service from CRP.

3.4.2 Sampling technique:

Purposive sampling was used to select participants. Purposive sampling helps to choose

participants who are most likely to provide relevant and helpful data (Kelly et al., 2010) and it is a method of choosing samples that will make efficient use of the few research resources available (Palinkas et al., 2015). Student researchers have established some inclusion and exclusion criteria to meet the right population for the study. Which is why purposive sampling is the most suitable.

3.4.3 Inclusion criteria:

- The primary family caregivers of people with SCI (Parents, Spouse, Siblings, Adult Child).
- At least 1 month experience of taking care of person with SCI.
- Caregiver's age at least 18 years.
- Participating voluntarily.

3.4.4 Exclusion criteria:

- Family members of patients with other physical condition rather than SCI.
- Family members not in contact with the person with SCI or do not provide care.
- Family caregivers who are not mentally stable.
- Family caregivers have gaps in duration of caregiving.

3.4.5 Sample size:

Sample size was estimated by using Cochran formula $n = \frac{z^2}{4d^2}$ (as sample population and population proportion is unknown).

Prevalence, P=As the prevalence of primary family caregiver of people with SCI is yield, so the prevalence of people with SCI was considered 50%.

Sample size= n,

Confidence Interval= 95%

Z value= the standard deviation usually set at 1.96,

Level of precision, d= 5%

$$\begin{aligned}
 \text{Sample size, } n &= \frac{Z^2}{\frac{4d^2}{(1.96)^2}} \\
 &= \frac{Z^2}{4(0.05)^2} \\
 &= 384.16 \sim 385
 \end{aligned}$$

Adding 10% non-response data to the actual sample size = 422.576~423

According to the equation the sample size was 423 participants. The researcher could collect data from 134 participants in this study.

3.5 Ethical Consideration

3.5.1 Ethical clearance:

The consent was sought from Institutional Review Board (IRB) explaining the purpose of research through the Department of Occupational Therapy, Bangladesh Health Professions Institute (BHPI). The IRB number: CRP-BHPI/IRB/10/2023/762. Permission was taken from CBR department and OT Department of Spinal Cord Injury before taking information from participants. The humanity and dignity of the participants was preserved.

All ethics were followed by the ethical principles of World Medical Association (WMA) and Declaration of Helsinki created for medical research (Kong et al., 2014; World Medical Association et al., 2022)

3.5.2 Informed consent:

- All participants were informed about the purpose, aim of the study and their roles in the study.

- All participation was voluntarily and written consent was taken from the participants.

3.5.3 Right of refusal to participate or withdraw:

In this study the participants were able to withdraw participation after two weeks of survey without any repercussion.

3.5.4 Unequal relationship:

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

3.5.5 Risk and beneficence:

The participants did not face any risk and no payment/beneficence were given.

3.5.6 Confidentiality:

The information provided by the participant were kept confidential. The names and identity were not disclosed to anyone except student researcher and supervisor. The participants were informed that their identity will be kept confidential for future uses, such as report writing, publication or any other written materials or verbal discussion.

3.6 Data Collection Process

3.6.1 Participant recruitment process

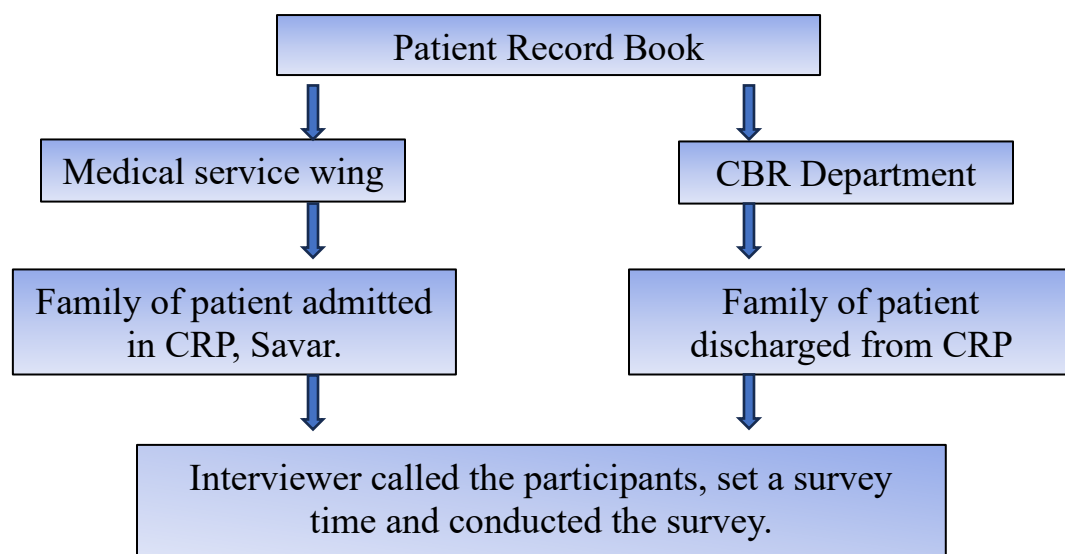


Figure 3.1: Overview of Participant recruitment process

Student researcher collected data from two groups of participants, one group was family caregiver of patient admitted in CRP who were contacted through patient record book of OT Department of Spinal Cord Injury of CRP. The name and bed no. were collected and later was interviewed in the patient ward. Another group of participants were contacted through the CBR department record book of patients who were living in community after getting discharged from CRP. Participants were contacted through the name, phone number and address collected from the record book. Interview was then scheduled with the patients and their family members and was visited accordingly. Data was collected from both groups who met the inclusion and exclusion criteria, by providing them with the research information and taking written consent.

3.6.2 Data collection method:

Student researcher collected data through face-to-face survey method. Face-to-face surveys are done by an interviewer who calls on, or meets with, the respondent and conducts the interview. It can be done in two ways one in the form of a paper-and-pencil interview (PAPI) another is a computer-assisted personal interview (CAPI). In both ways, interviewer reads out the questions and records the respondent's answers (Dykema et al., 2012). Face-to-face interview was done in this study by paper-pencil as the participants were within the reach of the student researcher and it provides better quality information even if more cumbersome and expensive (Bonnell & Le Nir, 1998).

3.6.3 Data collection instrument:

A self-developed questionnaire to collect socio-demographic data of primary family caregiver (Socio demographic factors included family members phone no., age, gender,

educational level, relationship with the patient, duration of care giving, monthly income and monthly expenditure).

Family Crisis Oriented Personal Evaluation Scales (F-COPES)

Hamilton McCubbin, David Olson, and Andrea Larsen (1981) developed The Family Crisis Oriented Personal Evaluation Scales (F-COPES). F-COPES identifies behavioral and problem-solving techniques used by families in challenging situations. This scale is based on coping elements of the Resiliency Model of Family Adjustment and Adaptation, which include pile-up, family resources, and meaning/perception. English is one of the four languages in which it is available. The 30 coping behavior items on the instrument center on the two levels of interaction in the Resiliency Model: (1) Family to social environment, which measures how a family reacts to issues that emerge outside of its boundaries; and (2) Individual to family system, which measures how a family handles difficulties/ disputes among its members and its impact (Crisis & Personal, n.d.). Each item has 5-points, ranging from always to never. It was proposed that families will handle stressful circumstances better if they use coping strategies that emphasize both levels of contact. There is evidence supporting the F-COPES's validity and reliability. Test-retest reliability ranges from .61-.95, and Cronbach's alpha from .62-.87 across a range of research. This instrument's validity has been established in multiple extensive investigations with stressed-out families. No training is required to administer. Subscale scores and a total score is to be calculated. Higher scores on the F-COPES indicate higher levels of coping and problem-solving abilities. The total potential score on the test ranges from 30 to 150. Inadequate coping is indicated by scores lower than 81 on the total score.

3.6.4 Field test:

A field test was conducted among 4 participants after translating the questionnaires into Bangla, the native language of Bangladesh. After field test modifications were made to the questionnaire taking permission from the tool's author. The questions 14, 23, 27 which are under the subscale seeking spiritual support were modified according to the country's cultural and religious context to help maintain questions quality.

3.6.5 Non-participant:

Data was collected from participant group (family primary caregivers) but at the time of interview few times other family member/ person with SCI answered on behalf and provided data being the non-participants of the study.

3.7 Data Management and Analysis

In this study data was managed following the five stages of data lifecycle management. Data was collected from 134 participants through face-to-face interviews using questionnaire and a standardized tool, answers were recorded in paper and pencil. Data was translated into English then entered without any biasness into the SPSS v.20 for storage and analysis. Data was also stored in Google drive storage system. Proper use was ensured by remaining conscious of using data as it is. All data was archived in Google drive. Student researcher and supervisor decided to destroy data after 5 years for maintaining proper data safety and valuation (Rahul & Banyal, 2020).

Socio-demographic data of the participant and items of F-COPES was analyzed through descriptive statistics. The student researcher specifically studied the socio-demographic attributes of age, gender, education level, relationship with the person with SCI, duration of caregiving, monthly income, monthly expenditure, and other

characteristics. For testing normality of continuous variables, the Kolmogorov-Smirnov test was used. Variables were described using ($p=0.05$) with 95% confidence intervals. Coping strategies that were used by family primary caregivers of a person with SCI were determined and compared among the two groups rehabilitation center and community by calculating mean and SD of each subscale score and total score of the F-COPES. Typically, based on raw sub-scale scores the score of F-COPES is interpreted. However, as the sub-scales have different number of items and possible range of total raw scores, we divided each sub-scale by the number of items in that particular sub-scale, thus allowing for comparisons across mean of the sub-scales. Association between rehabilitation center and community coping was seen through Mann-Whitney test of F-COPES total score and subscale score. The association between socio-demographic factors and F-COPES total score of the two groups was analyzed through Mann-Whitney and Kruskal Wallis tests.

3.8 Quality Control and Quality Assurance

The five stages of data management ensured data safety and quality in this study. Data collection and entry process was done without any biasness. All documents were photocopied and kept safe in a locked file cabinet to which only the student researcher had access. It was also stored in Google Drive storage system. The storage system was well protected by a strong password on Google securities. Security was maintained by not allowing any unauthorized access and later achieving the data. Data was properly used and were rechecked avoiding any modification or any sort of exploitation for data quality control and assurance.

CHAPTER IV: Results

4.1 Socio-demographic characteristics

Table 4.1

Socio-demographic characteristics of the participants

Variable		Rehabilitation Center		Community	
		n	%	n	%
Age	(18-44) years	46	68.7	49	73.1
	(45-70) years	21	31.3	18	26.9
		Mean(\pm SD) = 37.70 years (\pm 12.496) Minimum=18 years, Maximum=70 years		Mean(\pm SD) =35.70 years SD (12.388) Minimum=18 years, Maximum=70 years	
Gender	Male	18	26.9	16	23.9
	Female	49	73.1	51	76.1
Level of Education	Illiterate	0	0	2	3.0
	Signature	9	13.4	9	13.4
	Primary	22	32.8	10	14.9
	Secondary	13	19.4	22	32.8
	Higher Secondary	12	17.9	8	11.9
	Honors	7	10.4	8	11.9
	Tertiary	4	6.0	8	11.9
Religion	Muslim	67	100	59	88.1
	Hindu	0	0	7	10.4
	Christian	0	0	1	1.5
Occupati on	Housewife	42	62.7	36	53.7
	Unemployed	2	3.0	0	0
	Student	8	11.9	4	6.0
	Business	7	10.4	6	9.0
	Employed	8	11.9	21	31.3
Marital Status	Married	55	82.1	58	86.6
	Unmarried	6	9.0	7	10.4
	Widow	6	9.0	2	3.0
Duration of caregivin g	(1-9) months	63	94	0	0
	(10-18) months	4	6	0	0
	(1-216) months	0	0	60	89.6
	(217-432) months	0	0	7	10.4

Table 4.1*Socio-demographic characteristics of the participants*

		Mean(\pm SD) = 3.93 SD (\pm 3.149) Minimum=1 month, Maximum=18 months		Mean(\pm SD) =80.63 SD (\pm 95.981) Minimum=2 months, Maximum=432 months	
Monthly Income	(5000-49000) Tk	61	91	63	94
	(50000-100000) Tk	6	9	4	6
		Mean(\pm SD) = 20380.60 SD (\pm 12875.596) Minimum=7000tk, Maximum=50000tk		Mean(\pm SD) =22343.28 SD (\pm 15253.963) Minimum=5000tk, Maximum=100000tk	
Monthly Expendit ure	(5000-49000) Tk	61	91	63	94
	(50000-100000) Tk	6	9	4	6
		Mean(\pm SD) = 19492.54 SD (\pm 12785.377) Minimum=7000tk, Maximum=50000tk		Mean(\pm SD) =21265.67 SD (\pm 13064.937) Minimum=5000tk, Maximum=70000tk	

Table 4.1 shows an overview of the socio-demographic characteristics of the primary family caregiver of a person with SCI in two groups. In rehabilitation center, the mean age of the participants is 37.70 years SD (\pm 12.496) and 26.9% (18) were male, 73.1% (49) were female; in community, the mean age is 35.70 years SD (\pm 12.388) comprising of 23.9% (16) males and 76.1% (51) females. Most participants completed education up to primary level in rehab center and secondary level in community percentage being 32.8% (22) of both. Higher proportion of caregiver's occupation were housewives 62.7% (42) in rehabilitation center & 53.7% (36) in community. More were employed in the community 31.3% (21) compared to rehabilitation center 11.9% (8). The mean duration of caregiving in rehab center is found to be 3.93 months SD (\pm 3.149) while it is 80.63 months SD (\pm 95.981) in community which is comparatively much higher. In this sample, the mean of monthly income in rehab center and community with not much difference is reported 20380.60 BDT SD (\pm 12875.596) and 22343.28 BDT SD (\pm 15253.963). In case of monthly

expenditure, the mean is slightly more in community 21265.67 BDT SD (± 13064.937) than rehabilitation center 19492.54 BDT SD (± 12785.377).

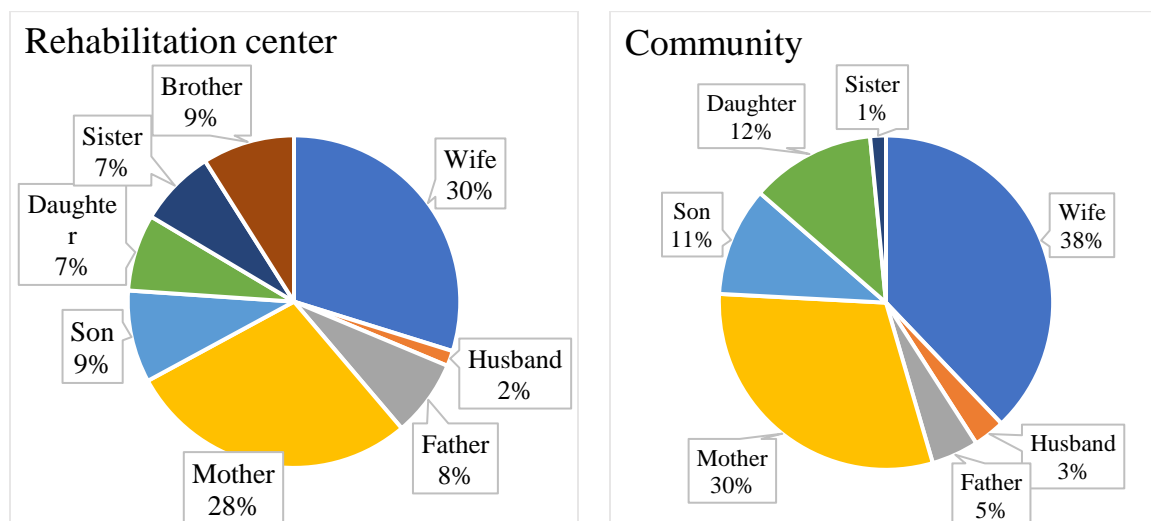


Figure 4.1: Overview of participant relationship with person with SCI

In figure 4.1 Regarding relationship with the patient, in rehab center highest number are wife 29.9% (20) and lowest is husband 1.5% (1) whereas in community also the highest number is wife (37.3%, 25) but the lowest is sister/brother 1.5% (1).

Normality of Socio-demographic variable and F-COPE scale: According to Kolmogorov-Smirnov test the socio-demographic variables (Age, Gender, Level of education, Relationship with person with SCI, Duration of caregiving, Monthly income and Monthly expenditure), the subscale score and total score of F-COPES are not normally distributed ($<p$) where $p=0.05$ both in rehabilitation center and community.

4.2 Overview of F-COPES item.

Table 4.2

Overview of F-COPES items in Rehabilitation center.

Rehabilitation Centre	Strongly disagree	Moderately disagree	Neither agree nor disagree	Moderately agree	Strongly agree	Mean (\pm SD)
(Items)	% (n)	% (n)	% (n)	% (n)	% (n)	
1. Sharing our difficulties with relatives	0 (0)	3 (2)	10.4 (7)	26.9 (18)	59.7 (40)	4.43 (\pm .802)
2. Seeking encouragement and support from friends	32.8 (22)	11.9 (8)	7.5 (5)	26.9 (18)	20.9 (14)	2.91 (\pm 1.602)
3. Knowing we have the power to solve major problems	14.9 (10)	17.9 (12)	40.3 (27)	22.4 (15)	45 (3)	2.84 (\pm 1.081)
4. Seeking information and advice from person in other families who have faced the same or similar problems	23.9 (16)	9 (6)	11.9 (8)	19.4 (13)	35.8 (24)	3.34 (\pm 1.610)
5. Seeking advice from relatives (grandparents, etc.)	11.9 (8)	4.5 (3)	11.9 (8)	22.4 (15)	49.3 (33)	3.93 (\pm 1.374)
6. Seeking assistance from community agencies and programs designed to help families in our situation	71.6 (48)	0	9 (6)	9 (6)	10.4 (7)	1.87 (\pm 1.455)
7. Knowing that we have the strength within our own family to solve our problems	16.4 (11)	17.9 (12)	38.8 (26)	13.4 (9)	13.4 (9)	2.90 (\pm 1.233)
8. Receiving gifts and favors from neighbors (e.g., food, taking in mail, etc.)	37.3 (24)	6 (4)	3 (2)	23.9 (16)	29.9 (20)	3.03 (\pm 1.741)
9. Seeking information and advice from the family doctor	55.2 (37)	6 (4)	7.5 (5)	6 (4)	25.4 (17)	2.40 (\pm 1.741)
10. Asking neighbors for favors and assistance	29.9 (20)	3 (2)	10.4 (7)	20.9 (14)	35.8 (24)	3.30 (\pm 1.679)
11. Facing the problems “head-on” and trying to get solution right away	6 (4)	17.9 (12)	28.4 (19)	29.9 (20)	17.9 (12)	3.36 (\pm 1.151)
12. Watching television	13.4 (9)	22.4 (15)	3 (2)	3 (2)	58.2 (39)	3.70 (\pm 1.633)
13. Showing that we are strong	17.9 (12)	26.9 (18)	14.9 (10)	19.4 (13)	20.9 (14)	2.99 (\pm 1.430)

Table 4.2*Overview of F-COPES items in Rehabilitation center.*

14. Attending church/ mosque/ temple	11.9 (8)	6 (4)	23.9 (16)	14.9 (10)	43.3 (29)	3.72 (±1.391)
15. Accepting stressful events as a fact of life	1.5 (1)	4.5 (3)	7.5 (5)	38.8 (26)	47.8 (32)	4.27 (±.898)
16. Sharing concerns with close friends	40.3 (27)	10.4 (7)	4.5 (3)	20.9 (14)	23.9 (16)	2.78 (±1.695)
17. Knowing luck plays a big part in how well we are able to solve family problems	56.7 (38)	28.4 (19)	10.4 (7)	1.5 (1)	3 (2)	1.66 (±.946)
18. Exercising with friends to stay fit and reduce tension	50.7 (34)	1.5 (1)	10.4 (7)	28.4 (19)	9 (6)	2.43 (±1.549)
19. Accepting that difficulties occur unexpectedly	3 (2)	4.5 (3)	9 (6)	28.4 (19)	55.2 (37)	4.28 (±1.012)
20. Doing things with relatives (get-together, dinners, etc.)	20.9 (14)	10.4 (7)	7.5 (5)	25.4 (17)	35.8 (24)	3.45 (±1.569)
21. Seeking professional counseling and help for family difficulties	92.4 (62)	0	3 (2)	0	4.5 (3)	1.24 (±.889)
22. Believing we can handle our own problems	6 (4)	1.5 (1)	9 (6)	53.7 (36)	29.9 (20)	4.00 (±1.000)
23. Participating in religious activities	26.9 (18)	3 (2)	25.4 (17)	31.3 (21)	13.4 (9)	3.01 (±1.409)
24. Defining the family problem in a more positive way so that we do not become too discouraged	1.5 (1)	14.9 (10)	13.4 (9)	35.8 (24)	34.3 (23)	3.87 (±1.100)
25. Asking relatives how they feel about problems we face	17.9 (12)	10.4 (7)	16.4 (11)	29.9 (20)	25.4 (17)	3.34 (±1.431)
26. Feeling that no matter what we do to prepare, we will have difficulty handling problems	13.4 (9)	38.8 (26)	26.9 (18)	10.4 (7)	10.4 (7)	2.66 (±1.162)
27. Seeking advice from a religious leader	34.3 (23)	3 (2)	7.5 (5)	19.4 (13)	35.8 (24)	3.19 (±1.743)
28. Believing if we wait long enough, the problem will go away	32.8 (22)	44.8 (30)	9 (6)	3 (2)	10.4 (7)	2.13 (±1.217)
29. Sharing problems with neighbors	11.9 (8)	10.4 (7)	7.5 (5)	40.3 (27)	29.9 (20)	3.66 (±1.332)
30. Having faith in God	0	0	0	1.5 (1)	98.5 (66)	4.99 (±.122)

In the above table 4.2, the 30 items represent the various coping strategies used by family caregivers in a rehabilitation center. Here, n=67. The items which the respondents most

strongly agree and found as helpful are sharing difficulties with relatives 59.7% (40) and accepting difficulties as unexpected 55.2% (37). Conversely, the items most strongly disagreed are “seeking assistance from community agencies and programs” 71.6% (48), and “knowing luck plays a big part in how well we are able to solve family problems” 56.7% (38). The respondents were neutral or moderately agreed/disagreed to the other items such as attending church/mosque/temple, believing they can solve their own problems, sharing problems with neighbors etc.

Table 4.3

Overview of F-COPES items in the Community

Community	Strongly disagree	Moderately disagree	Neither agree nor disagree	Moderately agree	Strongly disagree	Mean (±SD)
(Items)	% (n)	% (n)	% (n)	% (n)	% (n)	
1. Sharing our difficulties with relatives	11.9 (8)	9 (6)	7.5 (5)	23.9 (16)	47.8 (32)	3.87 (±1.413)
2. Seeking encouragement and support from friends	38.8 (26)	13.4 (9)	6 (4)	17.9 (12)	23.9 (16)	2.75 (±1.673)
3. Knowing we have the power to solve major problems	7.5 (5)	22.4 (15)	23.9 (16)	37.3 (25)	9 (6)	3.18 (±1.114)
4. Seeking information and advice from person in other families who have faced the same or similar problems	31.3 (21)	10.4 (7)	10.4 (7)	22.4 (15)	25.4 (17)	3.00 (±1.624)
5. Seeking advice from relatives (grandparents, etc.)	26.9 (18)	13.4 (9)	6 (4)	10.4 (7)	43.3 (29)	3.30 (±1.732)
6. Seeking assistance from community agencies and programs designed to help families in our situation	64.2 (43)	6 (4)	4.5 (3)	11.9 (8)	13.4 (9)	2.04 (±1.551)
7. Knowing that we have the strength with our own family to solve our problems	13.4 (9)	19.4 (13)	16.4 (11)	26.9 (18)	23.9 (16)	3.28 (±1.380)
8. Receiving gifts and favors from neighbors (e.g., food, taking in mail, etc.)	44.8 (30)	4.5 (3)	7.5 (5)	23.9 (16)	19.4 (13)	2.69 (±1.672)

Table 4.3*Overview of F-COPES items in the Community*

9. Seeking information and advice from the family doctor	50.7 (34)	3 (2)	13.4 (9)	10.4 (7)	22.4 (15)	2.51 (±1.691)
10. Asking neighbors for favors and assistance	34.3 (23)	6 (4)	4.5 (3)	31.3 (21)	23.9 (16)	3.04 (±1.655)
11. Facing the problems “head-on” and trying to get solution right away	3 (2)	22.4 (15)	32.8 (22)	22.4 (15)	19.4 (13)	3.33 (±1.120)
12. Watching television	20.9 (14)	10.4 (7)	7.5 (5)	11.9 (8)	49.3 (33)	3.58 (±1.653)
13. Showing that we are strong	19.4 (13)	16.4 (11)	11.9 (8)	20.9 (14)	31.3 (21)	3.28 (±1.535)
14. Attending church/mosque/temple	1.5 (1)	1.5 (1)	28.4 (19)	25.4 (17)	43.3 (29)	4.07 (±0.958)
15. Accepting stressful events as a fact of life	1.5 (1)	3 (2)	6 (4)	49.3 (33)	40.3 (27)	4.24 (±0.818)
16. Sharing concerns with close friends	49.3 (33)	4.5 (3)	7.5 (5)	10.4 (7)	28.4 (19)	2.64 (±1.781)
17. Knowing luck plays a big part in how well we are able to solve family problems	59.7 (40)	31.3 (21)	6 (4)	3 (2)	0	1.52 (±0.746)
18. Exercising with friends to stay fit and reduce tension	52.2 (35)	3 (2)	7.5 (5)	16.4 (11)	20.9 (14)	2.51 (±1.709)
19. Accepting that difficulties occur unexpectedly	0	1.5 (1)	7.5 (5)	47.8 (32)	43.3 (29)	4.33 (±0.683)
20. Doing things with relatives (get-together, dinners, etc.)	31.3 (21)	9 (6)	4.5 (3)	28.4 (19)	26.9 (18)	3.10 (±1.653)
21. Seeking professional counseling and help for family difficulties	89.6 (60)	0	0	6 (4)	4.5 (3)	1.36 (±1.069)
22. Believing we can handle our own problems	0	3 (2)	7.5 (5)	37.3 (25)	52.2 (35)	4.39 (±0.758)
23. Participating in religious activities	4.5 (3)	1.5 (1)	49.3 (33)	26.9 (18)	17.9 (12)	3.52 (±0.959)
24. Defining the family problem in a more positive way so that we do not become too discouraged	1.5 (1)	6 (4)	17.9 (12)	29.9 (20)	44.8 (30)	4.10 (±1.002)
25. Asking relatives how they feel about problems we face	32.8 (22)	7.5 (5)	10.4 (7)	31.3 (21)	17.9 (12)	2.94 (±1.566)
26. Feeling that no matter what we do to prepare, we will have difficulty handling problems	17.9 (12)	41.8 (18)	17.9 (12)	9 (6)	13.4 (9)	2.58 (±1.269)

Table 4.3*Overview of F-COPES items in the Community*

27. Seeking advice from a religious leader	37.3 (25)	4.5 (3)	6 (4)	14.9 (10)	37.3 (25)	3.10 (±1.793)
28. Believing if we wait long enough, the problem will go away	44.8 (30)	38.8 (26)	11.9 (8)	4.5 (3)	0	1.76 (±0.836)
29. Sharing problems with neighbors	14.9 (10)	7.5 (5)	7.5 (5)	28.4 (19)	41.8 (28)	3.75 (±1.450)
30. Having faith in God	1.5 (1)	0	0	0	98.5 (66)	4.94 (±0.489)

Table 4.3 shows the 30 items describing various coping strategies that are used by family caregivers in a community setting. Here, n=67. The items “believe they can handle their own problems” 52.2% (35) and “sharing difficulties with relatives” 47.8% (32) were the more strongly agreed on. Conversely, the items “seeking assistance from community agencies and programs” 64.2% (43) and “believing if we wait long enough, the problem will go away” 44.8% (30) shows strong disagreement. The respondents were neutral or moderately agreed/disagreed to the other items such as accepting stressful events as a fact of life, accepting that difficulties occur unexpectedly, participating in religious activities etc.

4.3 Mean results of subscales and overall scale

Table 4.4

Overview of mean and SD of F-COPE overall scale and subscale.

Scale	Rehabilitation center		Community		Total	
	Mean	SD	Mean	SD	Mean	SD
Overall	95.66	±10.147	94.72	±13.029	95.19	±11.643
Subscale 1: Acquiring social support	23.37	±5.184	28.07	±7.486	27.72	±6.424
Subscale 2: Reframing	28.49	±4.962	30.13	±4.428	29.31	±4.756
Subscale 3: Seeking spiritual support	14.91	±2.983	15.64	±2.627	15.28	±2.824
Subscale 4: Mobilizing family support	14.91	±2.983	8.91	±3.558	11.91	±4.446
Subscale 5: Passive appraisal	10.15	±2.420	9.45	±2.488	9.80	±2.470

Table 4.4 shows that family primary caregivers of person with SCI utilized each coping method to a greater or lesser extent. The overall mean scores of family coping in rehabilitation center 95.66, in community 94.72, and in total 95.19. This suggests that both the rehabilitation center and the community are perceived positively in terms of family coping. However, there's slightly more variability in perceptions within the community, indicated by a higher standard deviation.

The F-COPES score across the 5 subscales where the reframing method (28.49) was most used followed by social support (23.37) both in the rehabilitation center and in community. Passive appraisal method was utilized the least (10.15) in rehabilitation center and family support was the least utilized in community (8.91). Description of results of the

five subscales of F-COPES for the participants in rehab center and in community are given below:

Acquiring Social Support: It is a measurement of the participant's capacity to proactively seek out assistance from friends, neighbors, family members, and other acquaintances. The mean scores indicate community (28.07 ± 7.486) participants are actively seeking social support slightly more positively compared to rehabilitation center ($23.37, \pm 5.184$).

Reframing: This strategy emphasizes how well a person can redefine upsetting experiences to make them easier to handle. Again, the community ($30.13, \pm 4.428$) shows slightly higher mean scores compared to the rehabilitation center ($28.49, \pm 4.962$), indicating more active efforts in cognitive restructuring of thoughts.

Seeking Spiritual Support: It evaluates the person's capacity to find spiritual assistance. The participants in rehab center scored a lower mean of 14.91 than the compared community of 15.64 although the differences are minimal.

Mobilizing Family Support: It evaluates the participant's capacity to look for and accept assistance from others in the community. There seems to be a notable difference regarding this strategy, with the community showing lower mean scores compared to the rehabilitation center (8.91 vs. 14.91) suggesting that community might perceive less support from their families than rehabilitation center.

Passive Appraisal: It focuses on evaluating issues through the lens of inactive or passive behaviors, like avoidance. The participants scored much lower in both groups as compared to other coping strategies. The rehab center group and community group mean scores are 10.15 and 9.45, respectively where community shows slightly lower mean scores than rehabilitation center.

Overall, these findings suggest generally positive perceptions of coping efforts, with some variations in specific aspects such as family support and passive appraisal between rehabilitation center and community. The community tends to have higher standard deviations across most subscales, indicating more diverse perceptions than rehabilitation center.

4.4 Association between Rehabilitation center and Community coping.

Table 4.5

Association between Rehabilitation center and Community F-COPES score.

The non-parametric Mann Whitney test is used for variables with 2 levels (Islam, 2020).

Variable		n	Mean rank	Mann-Whitney	P value
F-COPES	Rehabilitation Center	67	69.13	2135	.626
	Community	67	65.87		
Acquiring Social Support	Rehabilitation Center	67	65.32	2098.500	.515
	Community	67	69.68		
Reframing	Rehabilitation Center	67	61.28	1827.500	.063
	Community	67	73.72		
Seeking spiritual support	Rehabilitation Center	67	62.91	1937	.168
	Community	67	72.09		
Mobilizing family support	Rehabilitation Center	67	94.00	469	.000
	Community	67	41.00		
Passive appraisal	Rehabilitation Center	67	73.21	1862	.086
	Community	67	61.79		

Table 4.5 illustrates the Mann-Whitney test comparing the mean ranks of the F-COPES variable between rehabilitation center and community. The test result shows rehabilitation Center (67): Mean rank = 69.13 and community (67): Mean rank = 65.87.

In this test, the p-value is 0.626, which is greater than 0.05, so there is insufficient evidence to reject the null hypothesis. In this context, there is no significant difference between the

mean ranks of the F-COPES variable in the rehabilitation center group compared to the community group.

However, subscales result of F-COPES reveals participants in rehabilitation centers differ significantly from those in the community in terms of their tendency to mobilize family support ($p = .000$, $p < 0.05$), while other coping strategies is not statistically significant at the conventional level ($p < .05$).

4.5 Association between Coping and Socio-demographic factors.

Table 4.6

Association between coping and socio-demographic variables of the participants (in rehabilitation center).

The non-parametric Mann Whitney test is used for variables with 2 levels (Islam, 2020).

Variable	Categories (2 levels)	n	F-COPES total score		
			Mean rank	Mann-Whitney	P value
Age	(18-44) years	46	32.65	421	.401
	(45-70) years	21	36.95		
Gender	Male	18	43	279	.022
	Female	49	30.69		
Duration of caregiving	(1-9) months	63	34.10	119.500	.863
	(10-18) months	4	32.38		
Monthly income	(5000-49000) Tk	61	33.31	141	.356
	(50000-100000) Tk	6	41.00		
Monthly expenditure	(5000-49000) Tk	61	33.31	141	.356
	(50000-100000) Tk	6	41.00		

Table 4.6 shows comparison of mean ranks across coping in rehabilitation center for various socio-demographic variables with 2 levels. There are no significant differences in mean ranks between age groups ($p = 0.401$), duration of caregiving ($p = 8.63$), monthly income ($p = 0.356$) and monthly expenditure ($p = 0.356$) where $p > 0.05$. Gender is the only variable that varied significantly for the use of coping strategies ($p = 0.022$, $p < 0.05$) in terms

of the total F-COPES score, with males mean rank (43) more than females (30.69). Thereby association may be present indicating males employ more family coping compared to females.

Table 4.7

Association between coping and level of education of the participants and relationship with person with SCI (in rehabilitation center)

The non-parametric Kruskal Wallis test is used for variables more than 2 levels (Islam, 2020).

Variable		Categories (>2 levels)	n	F-COPES total score			
				Mean rank	X ²	df	P value
Level of education	Illiterate		0	0	7.873	5	.163
	Signature		9	32.06			
	Primary		22	31.84			
	Secondary		13	29.88			
	Higher Secondary		12	33.00			
	Honors		7	38.43			
	Tertiary		4	58.88			
Relationship with person with SCI	Wife		20	30.93	6.747	7	.456
	Husband		1	39.50			
	Father		5	44.70			
	Mother		19	28.66			
	Son		6	42.50			
	Daughter		5	28.30			
	Sister		5	39.90			
	Brother		6	42.67			

Table 4.7 shows that for both variable: level of education (p=0.163) and the relationship with the person with SCI (p=0.456), with a p-value greater than 0.05 there are no significant association with coping of the participants in rehabilitation center.

Table 4.8

Association between coping and socio-demographic variables of the participants (in Community)

The non-parametric Mann Whitney test is used for variable with 2 levels (Islam, 2020).

Variable	Categories (2 levels)	n	F-COPES total score		
			Mean rank	Mann-Whitney	P value
Age	18-44	49	36.27	330	.116
	45-70	18	27.83		
Gender	Male	16	36.38	370	.576
	Female	51	33.25		
Duration of caregiving	(1-216) months	60	33.06	153.500	.246
	(217-432) months	7	42.07		
Monthly income	(5000-49000) Tk	63	33.69	106.500	.606
	(50000-100000) Tk	4	38.88		
Monthly expenditure	(5000-49000) Tk	63	33.69	106.500	.606
	(50000-100000) Tk	4	38.88		

Table 4.8 shows p-value is greater than 0.05 of family caregivers coping based on their age (p=0.116), gender (p= 0.576), duration of caregiving (p= 0.246), monthly income (p= 0.606) and based on monthly expenditure (p= 0.606). So there is no statistically significant difference in the mean ranks for all comparisons between the two categories of each variable.

Table 4.9

Association between coping and level of education of the participants and relationship with person with SCI (in Community)

The non-parametric Kruskal Wallis test is used for factors with more than 2 levels (Islam, 2020).

Variable		Categories (>2 levels)	n	Mean rank	F-COPES score		
					X ²	df	P value
Level of education	Illiterate	2	6.50	12.054	6	.061	
	Signature	9	23.39				
	Primary	10	31.70				
	Secondary	22	33.73				
	Higher Secondary	8	47.63				
	Honors	8	41.88				
	Tertiary	8	34.94				
Relationship with person with SCI	Wife	25	33.94	9.410	7	.225	
	Husband	2	59.00				
	Father	3	33.33				
	Mother	20	31.73				
	Son	7	24.79				
	Daughter	8	34.88				
	Sister	1	65.00				
	Brother	1	59.50				

Table 4.9 shows the two variables, level of education (p= 0.061) and the relationship with the person with SCI (p= 0.225), p-value greater than 0.05, so there is no statistically significant association with coping for the participants in community.

CHAPTER V: Discussion

In this study, the mean age of the participants in rehabilitation center is 37.70 years. On the other hand, in the community, the mean age is 35.70 years. Geographically, caregiver ages differ; younger mean ages was found in Brazil and India (Blanes et al., 2007; Raj et al., 2006) and higher mean ages seen in the USA (Elliott et al., 2008; Koszycki et al., 2010) and the UK (Weitzenkamp et al., 1997). The study's participants majority were female in both groups (73.1%) in rehabilitation center and (76.1%) in community which aligns with many previous studies (Chui et al., 2007; Koszycki et al., 2010; Schultz & Wood, 1989; Shewchuk et al., 1998). Regarding relationship with the person with SCI, most caregivers in this study were women where 34% were wife and 29% were mothers. Similarly, caregivers in Iran 29% were spouses and 23% were parents (Khazaeipour et al., 2017). This is consistent with the idea that, in many regions of the world, women tend to be caregivers. For instance, in UK 58% of caregivers were women, and females accounted for roughly 70% of family caregivers in other Asian countries (Zanini et al., 2022). This research found few male caregivers, in contrast to a study conducted in South India where most caregivers for patients with schizophrenia were male (Stanley et al., 2017).

The coping strategy that families in both community and rehabilitation centers most frequently endorsed were reframing. Items on the F-COPES reframing sub-scale reflect participant's ability to manage stressful events by redefining them. Families that employ reframing demonstrate a passive acceptance mindset and tend to deal with issues within the family rather than seeking outside assistance. Families that score highly on this measure are therefore unlikely to be actively looking for community services, friends, or extended

family help. It's possible that this reluctance to ask for help is due to worries about the stigma toward SCI in society. Many families with people living with SCI have experienced rejection or ostracism in the past, which has led to a mindset of inactivity or resistance to outside help.

Social support ranks second in terms of coping mechanisms employed among both groups. Lack of social support is not a recent discovery or something that only affects those who have SCI. This study is different to a study that listed "seeking social support" and "mobilizing family to acquire and accept help" as the third and fourth often employed techniques (Yeh et al., 1994) in Taiwan. Considering that social assistance has been shown to be an effective tool for preserving the emotional well-being of families facing chronic disease (Neville, 1998; Varni et al., 1993), it is good that families of individuals with SCI are using social services more frequently. Since lack of outside assistance may have detrimental effects on one's physical and mental health. Interventions that support caregivers in locating and utilizing nonjudgmental, supportive social interactions are therefore necessary.

The subscale "Seeking Spiritual Support" is related to religious practices and beliefs. It should come as no surprise that some people who have an illness that alters their lives go to religion for solace from such experiences. It is moderately used among participants in both groups. Many research has examined spiritual coping in populations with chronic illnesses, and it is becoming increasingly clear that in order for clinicians to fully understand their patients' illness experiences, they must also understand their spiritual or religious beliefs (Pendleton et al., 2002; Ross(née Waugh), 1995).

Mobilization of family support was utilized fourth in rehab center as families

struggle to cope. In rehab center 71% and in the community 64.2% did not seek assistance from community agencies or programs. This was the least used coping method in community but second least method used in rehab center which is in contrast with (Twyo et al., 2007).

The F-COPES Passive Appraisal sub-scale's items, the coping strategy which is used significantly the least in rehab center but second least in community aligns with the study in Hong Kong (Chui et al., 2007). Passive appraisal tactics minimize or deny an issue that may provide family members more time to come to terms with the condition or to avoid feeling overwhelmed by negative emotions (Danielson et al., 1993). Consequently, when faced with an unexpected stressful occurrence, families tended to employ more passive appraisal techniques. Yet, according to (Nyamathi et al., 1992) using denial excessively or for an extended period of time has detrimental impacts. Passive coping families often feel powerless to make a positive difference about the condition. Instead of dealing with these issues directly, these families may give over management of the person's condition to others, such the medical staff. In certain circumstances, this might be beneficial, but if families don't actively monitor the person's status, it might cause issues.

In terms of F-COPES subscales mean score participants in rehabilitation centers appear to differ significantly from those in the community in terms only one coping strategy that is their tendency to mobilize family support ($p = .000$, $p < 0.05$), while other coping strategies: acquiring social support ($p = .515$), reframing ($p = .063$), seeking spiritual support ($p = .168$), passive appraisal ($p = .086$) do not differ significantly. Significance was identified in various subscales in a study comparing Asian Americans and Caucasians and noteworthy findings were in reframing and the passive appraisal subscale (Twyo et al.,

2007).

The overall F-COPES scores in this study although suggest that there's a chance both groups employ useful coping mechanisms in response to issues or challenges that the families face, the overall mean scores of family coping: 95.66 for the rehabilitation center, 94.72 for the community, and 95.19 in total, there is no significant difference between individuals in the rehabilitation center and those in the community. This is in line with the study measuring coping in families with cancer patients who are in good physical health (Thoma et al., 1993) and in parents of child with autism (Troy et al., 2007) but in disagreement with previous comparative studies of caregivers coping of children with autism pre and post counselling program and coping strategies by stepfamilies and traditional nuclear families during pregnancy where there was significant differences in coping among two participant groups (Mevarech, 1982; Purnami, 2016). For both girls and boys, there were noteworthy correlations discovered between parental and child coping (Kliewer & Lewis, 1995), and among various illness groups (Brown et al., 1993; Kupst et al., 1995).

In the present study, there were hardly any significant statistical association of family caregivers coping with their sociodemographic characteristics. This is in line with what other research has shown (Hickman et al., 2010; Karabulutlu, 2014). Numerous research that contradicts the results of this one have suggested an association between specific coping mechanisms and socioeconomic status (Sheridan & Radmacher, 1992). According to Haan (2013), people with higher socioeconomic level are less likely to resort to defensive coping mechanisms like rigidity and irrationality and more likely to employ more adaptive coping mechanisms like flexibility, logical choice, and adherence to

consensual reality.

Unlike previous studies (O'Farrell et al., 2000; Santavirta et al. 2001), this study found no significant association between age and use of coping strategies neither in rehabilitation center nor in community. Similar findings were made by (Chui et al., 2007; Pompeo et al., 2016) regarding Hong Kong Chinese families, showing no significant variations in stress levels and coping mechanisms across age groups.

In rehabilitation center gender was only socio-demographic factor significantly associated with use of coping strategies indicating males employ more family coping compared to females this is consistent with the study where analysis indicated coping varied significantly among male and female caregivers (Ma et al., 2014), but no significant association was found in community among gender and coping strategies. This finding remain consistent with the study where no significance was found between gender and coping but the only noteworthy results concerned language and ethnicity (Twyo et al., 2007).

Coping is not statistically significant with the education level of caregivers in both rehabilitation center and community. This is consistent with the finding made by Martin et al. (2004) that no F-COPES sub-scale was substantially correlated with the degree of education of the caregiver, the family's race, the child's gender, or age (Martin et al., 2004). However, Pearlin and Schooler (1978) discovered that those who were more educated and wealthier were less likely to utilize selective ignoring while coping with marital and occupational issues. Higher educated respondents were shown to depend more on problem-focused coping strategies and to be less likely to adopt avoidance coping (Billings & Moos, 1984).

This study in rehabilitation center and community indicates no significant statistical difference in duration of caregiving with caregiver employ of coping. The results of previous studies, on the other hand, showed a favorable correlation between the length of caregiving and coping mechanisms (Guedes & Pereira, 2013) but in accordance with (Tway et al., 2007) reporting no significant association.

In this study there are no statistically significant differences in the mean ranks of the relationship categories with coping. This finding conflicts with studies (Guedes & Pereira, 2013) that demonstrate significant differences between other caregivers (in-laws, nephews, brothers) and spouses or children, with the latter group reporting higher use of coping mechanisms and (Pompeo et al., 2016) reporting a significant relationship between family relationships and self-control strategies, social support, and positive reappraisal. According to some research, coping strategies vary depending on the family composition (one-versus two-parent families) (Brazil & Krueger, 2002) and the caregiver's relationship to the child (biological versus alternative caregivers) (Rose, 1998).

No significant differences in mean ranks of monthly income, or monthly expenditure. Meaning that coping did not differ according to monthly income, or monthly expenditure neither in rehabilitation center nor in community. This result is consistent with research that found no statistically significant association between income and coping (Tway et al., 2007).

CHAPTER VI: Conclusion

6.1 Strength and Limitation

6.1.1 Strengths

- Data was collected through face-to-face interview which ensured more quality of information.
- Data collection process and entry was not biased.
- This study used a standardized questionnaire so easy comparison can be seen among two group of participants and consistency was maintained.
- The study tool was modified according to the participants culture and religious context.
- Study conducted among participants from two areas a) Rehabilitation center and b) Community.

6.1.2 Limitations

- Structured interview caused a limit in data depth and breath.
- The severity of the condition was not assessed. It is possible due to the variance this result was found.
- The number of participants were 134 which is significantly less than total sample size calculation. So, the coping strategy among family primary caregiver of person with SCI could not be generalized.

- This study did not include back-translation of the instrument (semi structured questionnaire) from Bangla to English, as per ITC requirements.

6.2 Practice Implication

6.2.1 Institution based practice implication.

The current rehabilitation program in CRP focuses more on people with SCI. Family caregiver coping can influence the work of occupational therapists who are involved in intervention of people with SCI. From the results of this study the items that caregivers in rehabilitation center strongly disagreed as we can see were seeking professional counseling and help (92.4%), seeking assistance from community agencies and programs (71.6%) and to know luck plays a big part in solving family problems (56.7%). Thereby recognizing these multifaceted needs interventions can be tailored to provide any training, counselling, or support services to help them fulfill caregiving responsibilities.

6.2.2 Community based practice implication

Occupational therapist should be the advocate for the families of people with SCI living in the community. They should make the person with SCI and the community aware of the family primary caregiver. Community is to be made aware of the needs, challenges, and rights of caregivers. This study finds that the caregivers in the community strongly disagreed on the items seeking professional counseling and help for family difficulties (89.6%), seeking assistance from community agencies and programs (64.2%) and exercising to reduce tension (52.2%). Occupational therapists can hence offer education about using effective coping strategies, counselling or design specific caregiving tasks or caregiver exercise program.

6.2.3 Recommendation for future practice:

- The coping strategies identified in this study will help direct future rehabilitation interventions. For example, perception of social support or seeking spiritual support.
- To include the families also in the treatment as early as possible.
- Endorsement of coping mechanisms to help client transition more successfully.
- Establishing an early rehabilitation program for family primary caregivers

6.2.4 Recommendation for future research:

- The study to be conducted on a large scale or a longitudinal study.
- To identify the quality of life of primary caregivers of people with SCI.
- Future study may adopt a qualitative approach.
- More than one member of the family maybe included to perceive individual family member coping.
- Multitude of coping questionnaires to be used.

6.3 Conclusion

The results of this study indicated that the family primary caregivers of person with SCI in a rehabilitation center and community most frequently used reframing. Spiritual support was reported as third in both areas. Passive appraisal is the least used by participants in rehabilitation center and family support is the least used in community. A significant difference is found in case of the coping strategy mobilizing family support between rehabilitation center and community and gender is the only sociodemographic variable that varied significantly for the use of coping strategies in rehabilitation center with males mean ranking more than females. As we know prioritizing caregiver coping allows occupational

therapists to better provide their clients with superior care. In light of these findings, caregiver education or counselling can be provided to help them mobilize family support or seeking spiritual support as these are used comparatively less than other strategies. The results of this study will provide guidance to therapists in Bangladesh on how to support families by providing culturally appropriate and competent interventions. Caregivers can be supported by conducting sessions in the clinical care settings to reinforce them to overcome challenges while taking care of a family member with SCI. In order to approach their work with clarity, empathy, and effectiveness and, ultimately, improve results for the people they serve, therapists must first of course manage their own stress and emotional well-being.

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Appendices

Appendix A: Approval Letter and Permission Letter

IRB Approval Letter



Ref: **CRP-BHPI/IRB/101-2023/762**

Date: **18-10-2023**

To
 Fariza Rehnuma Adiba
 4th Year B.Sc. in Occupational Therapy
 Session: 2018-2019; Student ID: 122180303
 Department of Occupational Therapy
 BHPI, CRP, Savar, Dhaka-1343, Bangladesh

Subject: Approval of the thesis proposal “Coping Strategies of Primary Family Caregivers of People with Spinal Cord Injury: A Cross-Sectional Study” by ethics committee.

Dear Fariza Rehnuma Adiba,
 Congratulations.

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

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

The purpose of the study is to assess the coping strategies of primary family caregivers of people with spinal cord injury. The study involves use of standardized scales (F-COPES: Family Crisis Oriented Personal Evaluation Scales) to measure the coping strategies that may take about 20 to 25 minutes to fill in the questionnaire for collection of specimens and there is no likelihood of any harm to the participants and no economic benefits for the participants. The members of the Ethics committee have approved the study to be conducted in the presented form at the meeting held at 8.30 AM on 23rd September 2023 at BHPI 38th 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,

Member Secretary
 Institutional Review Board
 BHPI, CRP, Savar, Dhaka-1343, Bangladesh.

Muhammad Millat Hossain
 Associate Professor
 Project & Course Coordinator
 Dept. of Rehabilitation Science
 BHPI, CRP, Savar, Dhaka-1343, Bangladesh

Permission Letter for Data Collection

Date: 19.10.2023

The Head of the Department
Department of Occupational Therapy
Bangladesh Health Professions Institute (BHPI)
CRP, Savar, Dhaka-1343, Bangladesh

Subject: Application for permission to collect data for the research project.

Sir,

With due respect, I would like to state that I am a student of 4th year, B.Sc. in Occupational Therapy at Bangladesh Health Professionals Institute (BHPI). I have to submit a research paper to the University of Dhaka in partial fulfillment of the degree of Bachelor of Science in Occupational Therapy. My research title is "Coping Strategies of Primary Family Caregivers of the People with Spinal Cord Injury" which is supervised by Luthfun Nahar, Lecturer in Occupational Therapy, Department of Occupational Therapy, Bangladesh Health Professions Institute (BHPI). This study aims to assess the coping strategies of primary family caregivers of people with SCI.

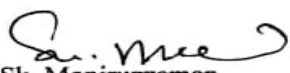
As it is a Quantitative research, I would like to collect data from primary family caregivers of person with SCI in Spinal Cord Injury unit in CRP, Savar and primary family caregivers of person with SCI living in the community. I assure you that anything in my study will not cause any harm to anyone and all the information gathered during the process will be kept confidential.

So, I look forward to having your permission to start data collection to conduct a successful study as a part of my course.

Sincerely yours,

Aliba
Fariza Rehnuma Adiba
4th Year B.Sc. in Occupational Therapy
Session: 2018-2019, Student ID: 122180303
Bangladesh Health Professions Institute (BHPI)
CRP-Savar, Dhaka-1343, Bangladesh

Signature and comments of The Head of The Department


Sk. Moniruzzaman
Head of the Department
Department of Occupational Therapy
Bangladesh Health Professions Institute (BHPI)
CRP-Savar, Dhaka-1343, Bangladesh

Date: 28.10.2023

To

The Head of the Department
Department of Occupational Therapy
Centre for the Rehabilitation of the Paralyzed (CRP)
Savar, Dhaka-1343, Bangladesh

Subject: Application for permission to collect data for the research project.

Sir,

With due respect, I would like to state that I am a student of 4th year. B.Sc. in Occupational Therapy at Bangladesh Health Professions Institute (BHPI). I have to submit a research paper to the University of Dhaka in partial fulfillment of the degree of Bachelor of Science in Occupational Therapy. My research title is "Coping Strategies of Primary Family Caregivers of the People with Spinal Cord Injury" which is supervised by Luthfun Nahar, Lecturer in Occupational Therapy, Department of Occupational Therapy, Bangladesh Health Professions Institute (BHPI). This study aims to assess the coping strategies of primary family caregivers of people with SCI.

As it is a Quantitative research. I would like to collect data from primary family caregivers of person with SCI in Spinal Cord Injury unit in CRP, Savar and primary family caregivers of person with SCI living in the community. I assure you that anything in my study will not cause any harm to anyone and all the information gathered during the process will be kept confidential.

So, I look forward to having your permission to start data collection to conduct a successful study as a part of my course.

Sincerely yours,

Adiba

Fariza Rehnuma Adiba

4th Year B.Sc. in Occupational Therapy

Session: 2018-2019, Student ID: 122180303

Bangladesh Health Professions Institute (BHPI)

CRP-Savar, Dhaka-1343, Bangladesh

Signature and comments of The Head of The Department

MD. Tauhidul Islam

Act. Head of the Department of Occupational Therapy

Centre for the Rehabilitation of the Paralyzed (CRP)

Savar, Dhaka-1343, Bangladesh

MD. Tauhidul Islam
28/10/2023

Date: 19.10.2023

To
 Manager
 Rehabilitation wing
 Centre for the Rehabilitation of the Paralysed
 Savar, Dhaka-1343, Bangladesh

CRP Coordinator

Assist Adiba for
 study data (caregivers)

Samin Rahman (1014)
 19/10/2023

Subject: Application for permission to collect data for the research project.

Sir,

With due respect, I would like to state that I am a student of 4th year, B.Sc. in Occupational Therapy at Bangladesh Health Professions Institute (BHPI). I have to submit a research paper to the University of Dhaka in partial fulfillment of the degree of Bachelor of Science in Occupational Therapy. My research title is "Coping Strategies of Primary Family Caregivers of the People with Spinal Cord Injury" which is supervised by Luthfun Nahar, Lecturer in Occupational Therapy, Department of Occupational Therapy, Bangladesh Health Professions Institute (BHPI). This study aims to assess the coping strategies of primary family caregivers of people with SCI.

As it is a Quantitative research, I would like to collect data from primary family caregivers of person with SCI in Spinal Cord Injury unit in CRP, Savar and primary family caregivers of person with SCI living in the community. I assure you that anything in my study will not cause any harm to anyone and all the information gathered during the process will be kept confidential.

So, I look forward to having your permission to start data collection to conduct a successful study as a part of my course.

Sincerely yours,

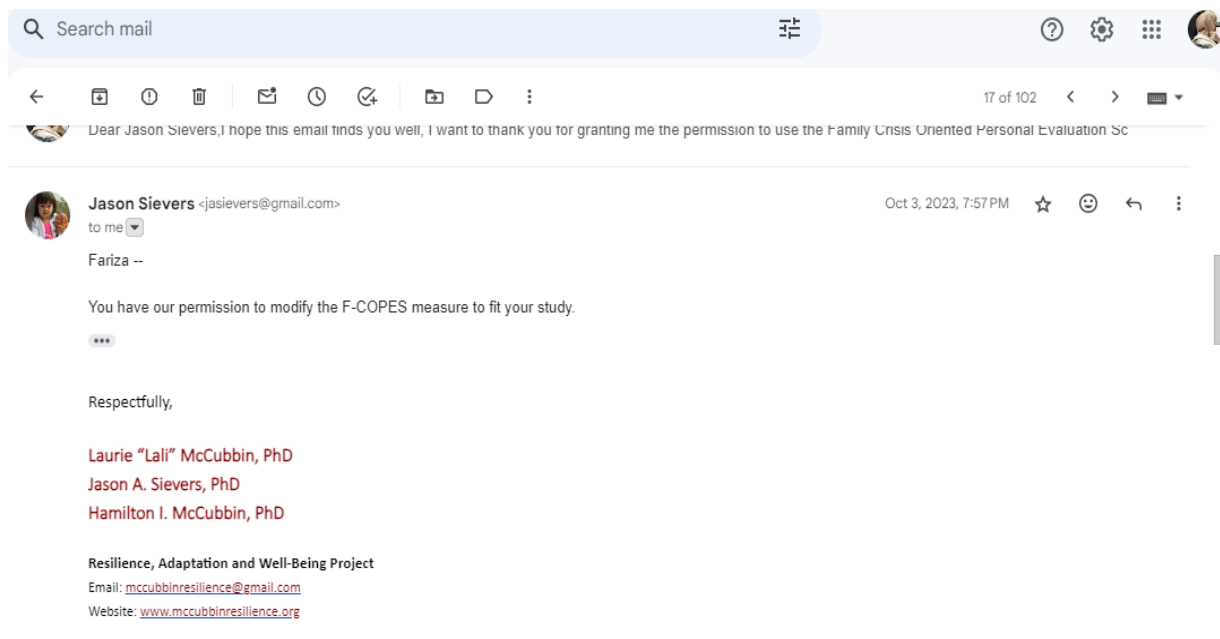
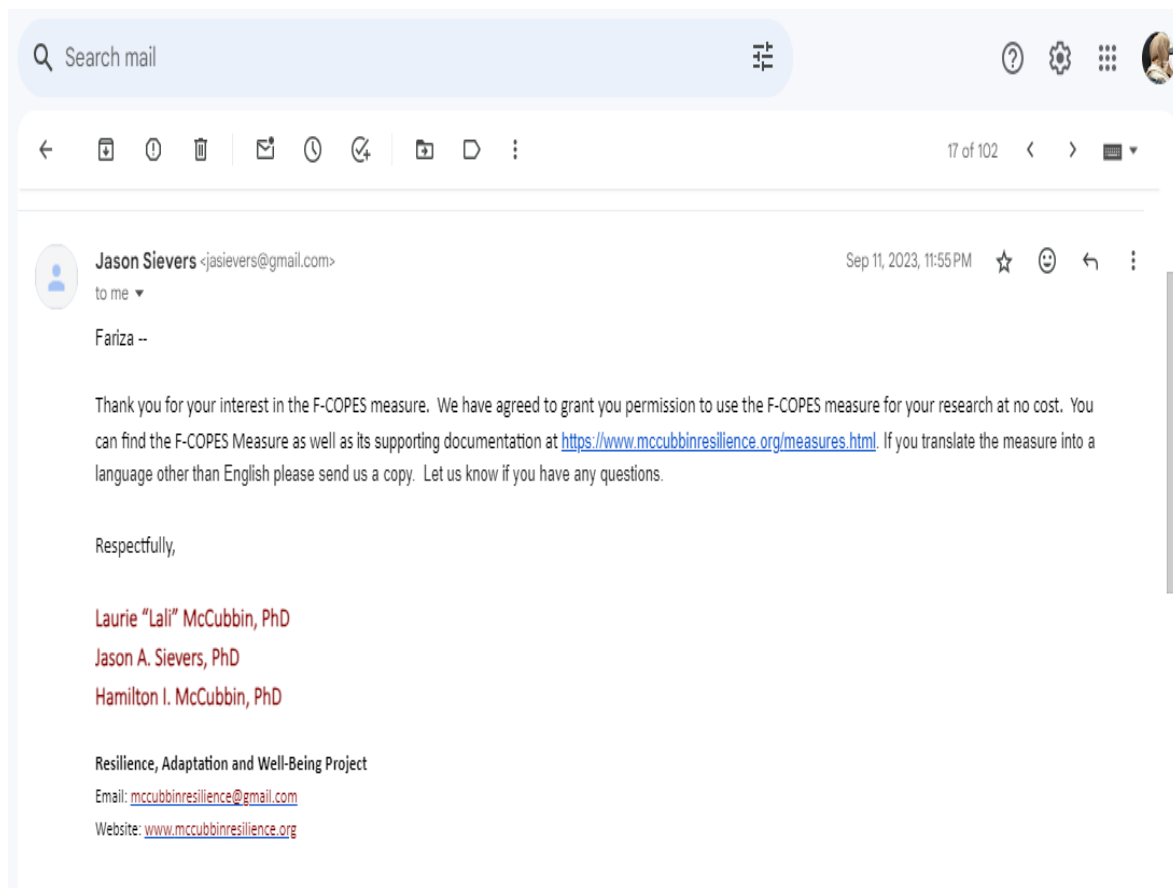
Adiba

Fariza Rehnuma Adiba
 4th Year B.Sc. in Occupational Therapy
 Session: 2018-2019, Student ID: 122180303
 Bangladesh Health Professions Institute (BHPI)
 CRP-Savar, Dhaka-1343, Bangladesh

Signature and comments:

Samin Rahman (1014)
 Salin Rahman
 Manager
 Rehabilitation wing
 CRP, Savar, Dhaka-1343, Bangladesh

Permission for using and modifying F-COPE Scale



Appendix B: Information Sheet, Consent Form and Withdrawal Form
(English version)

Bangladesh Health Professions Institute
Occupational Therapy Unit
CRP, Savar, Dhaka-1343

Information Sheet (English)

Title of the study: Coping Strategies of Primary Family Caregivers of the People with Spinal Cord Injury: A Cross-Sectional Study

Name of researcher: Fariza Rehnuma Adiba, 4th year, B.Sc. in Occupational Therapy.

You are invited to participate in a research study. Before deciding to participate, it is crucial that you understand the purpose of the study, what will be asked of you, and your rights as a participant. Please read the information below and feel free to ask any questions you may have.

Who am I and what is this study about:

I am Fariza Rehnuma Adiba, a student of 4th year, B. Sc in Occupational Therapy, Department of Occupational Therapy, Bangladesh Health Professions Institute (BHPI), the academic institute of Centre for the Rehabilitation of the Paralysed (CRP). As a part of my academic course curriculum, I am obliged to conduct a dissertation this academic year. The title of my study is "Coping Strategies of Primary Family Caregivers of the People with Spinal Cord Injury: A Cross-Sectional Study." The aim of this study is to assess the coping strategies of primary family caregivers of people with SCI and its associated factors.

The study is supervised by Luthfun Nahar, lecturer of Occupational Therapy Department, Bangladesh Health Professions Institute (BHPI), CRP, Savar, Dhaka.

What are the reasons for participating in this study?

I will be measuring the coping strategies of primary family caregivers of people with SCI. For which a self-developed questionnaire will be used for socio-demographic information and a scale to measure the coping strategies. Participants will be answering all the questions. Before participating you will be presented with detailed information about the conduct of the research study and consent will be taken. If you are unable to sign for any reason, in that case thumb impression will be taken in presence of a witness. Information will be collected from you through a questionnaire at any given time. Your participation in this study is optional. You do not have to consent; you do not have to participate. After giving consent within 2 weeks you may withdraw without giving any explanation to the researcher.

Why are you invited to participate in this study?

Participants who are willing and meets the inclusion criteria of the study are invited to participate.

Do you have to participate?

Participation in the study is entirely voluntary and up to the participant's will. Before participation consent will be taken and after participating, they will be accounted to answer all the questions. You have the right to withdraw your consent and discontinue participation

after two weeks of conducting survey without any repercussions.

How long will it take?

Time taken would be 20-30 minutes for the researcher to collect all information related to the study.

What are the possible risks and benefits of participation?

The participant will not get any direct benefit for participating in this research, however the information gained from this research will be contributed for future development and improvement of rehabilitation services. Participants will not face any type of problem or harm, participating in the research but can feel psychological discomfort while sharing their tough experience. If this problem arises during the interview the student research will take a break or discuss re-scheduling the interview. Participants can also withdraw their consent according to their wish.

Will the participation be confidential?

All information collected during this study will be strictly kept confidential by maintaining secrecy. No information will be shared with anyone else outside of the study unless it is required by the law. Only the student researcher and supervisor are allowed to access the data here. The participants will not be named in any reports, publications, or presentations that may come from this study. Information paper will be locked in a drawer, in the personal laptop of the student researcher and lock cloud system.

What will be the result of the study?

The findings of this research will help not only the families but also the person with SCI by promoting emotional and physical well-being, better care and family cohesion. Occupational therapists will be directed to consider the family members when providing treatment to the person with SCI by identifying the coping strategies that is employed by the primary family caregivers which will explain their experiences and challenges. The results will help enrich Department of Occupational Therapy by improving education, intervention plan and support services reinforcing holistic and family centered care. Furthermore, the results will also add insights for future literature about the importance of coping strategies of not only the patient but their families ultimately leading to better outcomes for both patient and his family.

The result of the study may be published in a scientific journal.

For more information, please contact the address below:

Student researcher: Fariza Rehnuma Adiba

B.Sc. in Occupational Therapy

Session: 2018-19, Roll: 06

BHPI, CRP, Savar, Dhaka.

Contact number: 01853357455.

Email: farizarehnuma@gmail.com

Supervisor: Luthfun Nahar

Lecturer in Occupational Therapy

Department of Occupational Therapy

BHPI, CRP, Savar, Dhaka.

Contact number: 01868846373.

Email: liza317@gmail.com

Consent Form (English)

Title of the study: Coping Strategies of Primary Family Caregivers of the People with Spinal Cord Injury: A Cross-Sectional Study

I am Fariza Rehnuma Adiba (Researcher), 4th year student, B.Sc. in Occupational Therapy, Bangladesh Health Professions Institute (BHPI) the academic institute of Centre for the Rehabilitation of the Paralysed (CRP). This study is a part of the curriculum of Department of Occupational Therapy. The study is supervised by Luthfun Nahar, lecturer of Occupational Therapy Department, Bangladesh Health Professions Institute (BHPI), CRP, Savar, Dhaka.

The participants are informed about the purpose and their role in the study. After knowing all the information participant will decide to participate. After getting consent researcher will begin data collection.

The participants will not be harmed in any way. The confidentiality of participation will be strictly maintained.

Participants have the right to withdraw without any repercussion within 2 weeks of data collection.

I am _____, I have read the above statement, understand the nature of my participation in the research, and I freely consent to participate. I recognize my right to withdraw my consent and discontinue participation in the study at any time up to 2 weeks of survey without fear of any prejudice and recognize that my activities and data generated by my participation will remain strictly confidential.

Name of the participant _____

Signature of participant/thumb print _____

Date _____

Student researcher's signature _____

Date _____

Withdrawal form (English)

Title of the study: Coping Strategies of Primary Family Caregivers of the People with Spinal Cord Injury: A Cross-Sectional Study

I _____, confirm that I wish to withdraw my consent to the use of data arising from my participation.

Reason for withdrawal _____

Name of the participant _____

Signature of participant/thumbprint _____

Date _____

(Bangla version)

বাংলাদেশ হেল্থ প্রফেশনস ইন্সটিটিউট (বিএইচপিআই)

অকুপেশনাল থেরাপি বিভাগ

সিআরপি, সাভার, ঢাকা-১৩৪৩

তথ্যপত্র (বাংলা)

গবেষণার শিরোনাম: মেরুদণ্ডের আঘাতে আক্রান্ত ব্যক্তিদের প্রাথমিক পরিবার পরিচর্যাকারীদের মোকাবিলা করার কৌশল: একটি ক্রস-বিভাগীয় অধ্যয়ন।

গবেষকের নাম: ফারিজা রেহনুমা আদিবা, ৪র্থ বর্ষ, বি.এসসি. ইন অকুপেশনাল থেরাপি।

আপনি একটি গবেষণায় অংশগ্রহণ করার জন্য আমন্ত্রিত। অংশগ্রহণ করার সিদ্ধান্ত নেওয়ার আগে, আপনি অধ্যয়নের উদ্দেশ্য, আপনাকে কী জিজ্ঞাসা করা হবে এবং একজন অংশগ্রহণকারী হিসাবে আপনার অধিকারগুলি বোঝা গুরুত্বপূর্ণ। অনুগ্রহ করে নিচের তথ্য পড়ুন এবং আপনার যে কোন প্রশ্ন থাকলে তা নির্দিধায় করুন।

আমি কে এবং এই গবেষণার উদ্দেশ্য:

আমি ফারিজা রেহনুমা আদিবা, ৪র্থ বর্ষের ছাত্রী, বি.এসসি ইন অকুপেশনাল থেরাপি, অকুপেশনাল থেরাপি বিভাগ, বাংলাদেশ হেল্থ প্রফেশনস ইনস্টিটিউট (বিএইচপিআই), সেন্টার ফর দ্য রিহাবিলিটেশন অব দ্য প্যারালাইজড (সিআরপি) এর একটি শিক্ষা প্রতিষ্ঠান। আমার কোর্স পাঠ্যক্রমের একটি অংশ হিসাবে, আমি এই শিক্ষাবর্ষে একটি গবেষণা পরিচালনা করতে বাধ্য। আমার অধ্যয়নের শিরোনাম হল " মেরুদণ্ডের আঘাতে আক্রান্ত ব্যক্তিদের প্রাথমিক পরিবার পরিচর্যাকারীদের মোকাবিলা করার কৌশল: একটি ক্রস-বিভাগীয় অধ্যয়ন।" এই অধ্যয়নের লক্ষ্য হল মেরুদণ্ডের আঘাতে আক্রান্ত ব্যক্তিদের প্রাথমিক পরিবার পরিচর্যাকারীদের মোকাবেলার কৌশলগুলি মূল্যায়ন করা।

অকুপেশনাল থেরাপি বিভাগের প্রভাষক লুৎফুন নাহার, বাংলাদেশ হেল্থ প্রফেশনস ইনস্টিটিউট (বিএইচপিআই), সিআরপি, সাভার, ঢাকা এই গবেষণার তত্ত্বাবধান করছেন।

এই গবেষণায় অংশগ্রহণের কারণগুলি কী কী?

আমি মেরুদণ্ডের আঘাতে আক্রান্ত ব্যক্তিদের প্রাথমিক পরিবার পরিচর্যাকারীদের মোকাবেলার কৌশলগুলি পরিমাপ করবো। যার জন্য একটি স্ব-বিকাশিত প্রশ্নাবলী সামাজিক-ডেমোগ্রাফিক তথ্যের জন্য এবং মোকাবিলা কৌশলগুলি পরিমাপের জন্য একটি স্কেল ব্যবহার করা হবে। অংশগ্রহণকারীরা সব প্রশ্নের উত্তর দেবেন। অংশগ্রহণের আগে আপনাকে গবেষণা পরিচালনার বিষয়ে বিস্তারিত তথ্য উপস্থাপন করা হবে এবং সম্মতি নেওয়া হবে। আপনি যদি কোনও কারণে স্বাক্ষর করতে অক্ষম হন তবে সেক্ষেত্রে সাক্ষীর উপস্থিতিতে আঙ্গুলের ছাপ নেওয়া হবে। যে কোনও সময়ে একটি প্রশ্নাবলীর মাধ্যমে আপনার কাছ থেকে তথ্য সংগ্রহ করা হবে। এই গবেষণায় আপনার অংশগ্রহণ ঐচ্ছিক। আপনাকে সম্মতি দিতে হবে না; আপনাকে অংশগ্রহণ করতে হবে না। ২ সপ্তাহের মধ্যে সম্মতি দেওয়ার পরে আপনি গবেষককে কোনও ব্যাখ্যা না দিয়ে প্রত্যাহার করতে পারেন।

কেন আপনি এই গবেষণায় অংশ নিতে আমন্ত্রিত?

অংশগ্রহণকারীরা যারা ইচ্ছুক এবং গবেষণার অন্তর্ভুক্তির মানদণ্ড পূরণ করে তারা অংশগ্রহণের জন্য আমন্ত্রিত।

আপনার কি অংশগ্রহণ করতে হবে?

গবেষণায় অংশগ্রহণ সম্পূর্ণরূপে স্বেচ্ছায় এবং সম্মতি নেওয়া হবে। অংশগ্রহণের পরে, তাদের সমস্ত প্রশ্নের উত্তর দিতে হবে। আপনার সম্মতি প্রত্যাহার করার এবং কোনও প্রতিক্রিয়া ছাড়াই জরিপ পরিচালনার দুই সপ্তাহ পরে অংশগ্রহণ বন্ধ করার অধিকার রয়েছে।

কত সময় লাগবে?

গবেষকের গবেষণা সম্পর্কিত সমস্ত তথ্য সংগ্রহ করার জন্য ২০-৩০ মিনিট সময় নেওয়া হবে।

অংশগ্রহণের সম্ভাব্য ঝুঁকি এবং সুবিধাগুলি কী কী?

অংশগ্রহণকারী এই গবেষণায় অংশগ্রহণের জন্য সরাসরি কোনো সুবিধা পাবেন না, তবে এই গবেষণা থেকে প্রাপ্ত তথ্য ভবিষ্যতের উন্নয়ন এবং পুনর্বাসন সেবা উন্নতির জন্য অবদান রাখবে। অংশগ্রহণকারীরা গবেষণায় অংশগ্রহণ করে কোনো ধরনের সমস্যা বা ক্ষতির সম্মুখীন হবে না কিন্তু তাদের কঠিন অভিজ্ঞতা নিয়ে বলার সময় মানসিক অস্থিতি অনুভব করতে পারে। সাক্ষাৎকারের সময় যদি এই সমস্যাটি দেখা দেয় তবে শিক্ষার্থী গবেষক একটি বিরতি নেবে বা পুনরায় সাক্ষাৎকারের সময়সূচী নিয়ে আলোচনা করবে। অংশগ্রহণকারীরা তাদের ইচ্ছা অনুযায়ী তাদের সম্মতি প্রত্যাহার করতে পারেন।

অংশগ্রহণ কি গোপনীয় হবে?

এই গবেষণার সময় সংগৃহীত সমস্ত তথ্য কঠোরভাবে গোপন রাখা হবে। আইনের প্রয়োজন না হলে অধ্যয়নের বাইরে অন্য কারো সাথে কোনো তথ্য প্রদান করা হবে না। শুধুমাত্র শিক্ষার্থী গবেষক এবং গবেষণার তত্ত্বাবধায়ক তথ্য সংগ্রহ করতে পারবেন। এই গবেষণা থেকে আসা কোনো প্রতিবেদন, প্রকাশনা বা উপস্থাপনায় অংশগ্রহণকারীদের নাম দেওয়া হবে না। তথ্য কাগজ একটি ড্রয়ারে লক করা থাকবে, শিক্ষার্থী গবেষকের ব্যক্তিগত ল্যাপটপে এবং লক ক্লাউড সিস্টেম।

গবেষণার ফলাফল কী হবে?

এই গবেষণার ফলাফল কেবল শুধু পরিবার নয়, মেরুদণ্ডের আঘাতে আক্রান্ত ব্যক্তিদের ও মানসিক এবং শারীরিক সুস্থতা, আরও ভাল যত্ন এবং পারিবারিক সংহতি প্রচার করতে সহায়তা করবে। প্রাথমিক পরিবারের পরিচর্যাকারীদের দ্বারা নিযুক্ত মোকাবিলা কৌশলগুলি চিহ্নিত করে তাদের অভিজ্ঞতা এবং সমস্যাগুলো ব্যাখ্যা করার মাধ্যম অকুপেশনাল থেরাপিস্টদের মেরুদণ্ডের আঘাতে আক্রান্ত ব্যক্তিদের চিকিৎসা দেওয়ার সময় পরিবারের সদস্যদের বিবেচনা করার নির্দেশ দিবে। ফলাফলগুলি শিক্ষা, চিকিৎসা পরিকল্পনা এবং সহায়তা পরিষেবাগুলি সামগ্রিক এবং পরিবার কেন্দ্রিক যত্নকে শক্তিশালী করে অকুপেশনাল থেরাপি বিভাগকে সমৃদ্ধ করতে সহায়তা করবে। তদুপরি, ফলাফলগুলি কেবল রোগীই নয়, তাদের পরিবারের মোকাবিলা করার কৌশলগুলির গুরুত্ব সম্পর্কে ভবিষ্যতের সাহিত্যের অন্তর্দৃষ্টি যুক্ত করবে যা রোগী এবং তার পরিবার উভয়ের জন্য আরও ভাল ফলাফলের দিকে পরিচালিত করবে।

গবেষণার ফলাফল একটি বৈজ্ঞানিক জার্নালে প্রকাশিত হতে পারে।

আরও তথ্যের জন্য, নীচের ঠিকানায় যোগাযোগ করুন

গবেষক: ফারিজা রেহনুমা আদিবা
 বি.এসসি. ইন অকুপেশনাল থেরাপি।
 অধিবেশন: ২০১৮-১৯, রোল: ০৬
 বিএইচপিআই, সিআরপি, সাভার, ঢাকা।
 যোগাযোগের নম্বর: ০১৮৫৩৩৫৭৪৫৫
 ইমেইল: farizarehnuma@gmail.com
 তত্ত্বাবধায়কঃ লুৎফুন নাহার
 অকুপেশনাল থেরাপির প্রভাষক
 অকুপেশনাল থেরাপি বিভাগ
 বিএইচপিআই, সিআরপি, সাভার, ঢাকা।
 যোগাযোগের নম্বর: ০১৮৬৮৮৪৬৩৭৩।
 ইমেইল: liza317@gmail.com

সম্মতি পত্র (বাংলা)

গবেষণার শিরোনাম: মেরুদণ্ডের আঘাতে আক্রান্ত ব্যক্তিদের প্রাথমিক পরিবার পরিচর্যািকারীদের মোকাবিলা করার কৌশল: একটি ক্রস-বিভাগীয় অধ্যয়ন।

আমি ফারিজা রেহনুমা আদিবা, ৪র্থ বর্ষের ছাত্রী, বি.এসসি ইন অকুপেশনাল থেরাপি, অকুপেশনাল থেরাপি বিভাগ, বাংলাদেশ হেলথ প্রফেশনস ইনস্টিটিউট (বিএইচপিআই), সেন্টার ফর দ্য রিহাবিলিটেশন অব দ্য প্যারালাইজড (সিআরপি) এর একটি শিক্ষা প্রতিষ্ঠান। এই গবেষণাটি অকুপেশনাল থেরাপি বিভাগের পাঠ্যক্রমের একটি অংশ। উক্ত গবেষণাটির তত্ত্বাবধায়ক লুৎফুন নাহার, অকুপেশনাল থেরাপি বিভাগ, বাংলাদেশ হেলথ প্রফেশনস ইনস্টিটিউট (বিএইচপিআই), সিআরপি, সাভার, ঢাকা।

অংশগ্রহণকারীদের উদ্দেশ্য এবং গবেষণায় তাদের ভূমিকা সম্পর্কে অবহিত করা হয়েছে। সমস্ত তথ্য জানার পরে অংশগ্রহণকারী অংশগ্রহণের সিদ্ধান্ত নেবে। সম্মতি পাওয়ার পর গবেষক তথ্য সংগ্রহ শুরু করবে। অংশগ্রহণকারীদের কোনওভাবে ক্ষতি করা হবে না। অংশগ্রহণের গোপনীয়তা কঠোরভাবে রক্ষা করা হবে। অংশগ্রহণকারীদের তথ্য সংগ্রহের ২ সপ্তাহের মধ্যে কোনও প্রতিক্রিয়া ছাড়াই প্রত্যাহার করার অধিকার রয়েছে।

আমি, _____ আমি উপরের বিবৃতিটি পড়েছি, গবেষণায় আমার অংশগ্রহণের প্রকৃতি বুঝতে পেরেছি এবং আমি স্বাধীনভাবে অংশগ্রহণ করতে সম্মত। আমি আমার সম্মতি প্রত্যাহার করার এবং কোনও ভয় ছাড়াই জরিপের ২ সপ্তাহের মধ্যে যে কোনও সময় অধ্যয়নে অংশগ্রহণ বন্ধ করার অধিকার স্বীকার করি এবং স্বীকার করি যে আমার অংশগ্রহণের মাধ্যমে উৎপন্ন আমার ক্রিয়াকলাপ এবং তথ্য কঠোরভাবে গোপনীয় থাকবে।

অংশগ্রহণকারীর নাম _____

অংশগ্রহণকারীর স্বাক্ষর/ টিসই _____

তারিখ _____

ছাত্রগবেষকের স্বাক্ষর _____

তারিখ _____

অংশগ্রহণকারীর প্রত্যাহার পত্র (বাংলা)

গবেষণার শিরোনামঃ মেরুদণ্ডের আঘাতে আক্রান্ত ব্যক্তিদের প্রাথমিক পরিবার পরিচর্যাকারীদের মোকাবিলা করার কৌশল: একটি ক্রস-বিভাগীয় অধ্যয়ন।

আমি _____ নিশ্চিত করছি যে আমি আমার অংশগ্রহণ থেকে উৎপন্ন তথ্য ব্যবহারে আমার সম্মতি প্রত্যাহার করতে চাই।

প্রত্যাহারের কারণ: _____

অংশগ্রহণকারীর নাম _____

অংশগ্রহণকারীর স্বাক্ষর/টিপসই _____

তারিখ _____

Appendix C: Questionnaire

Sociodemographic information (English Version)

Age: _____

Gender: Male Female Transgender

Present address: _____

Contact number: _____

Level of education: _____

Occupation: _____

Marital status: Married Unmarried Divorced

Separated Widow

Children (Yes/No): if yes how many: _____

Family type: Extended Nuclear

Number of family members: _____

Relationship with the patient: _____

Duration of patient's injury: _____

Stage of treatment: _____

Duration of caregiving: _____

Monthly income: _____

Source of income: _____

Monthly expenditure: _____

Earning member of family: _____

Sociodemographic information (Bangla version)

বয়সঃ _____

লিঙ্গঃ পুরুষ নারী তৃতীয় লিঙ্গ

বর্তমান ঠিকানাঃ _____

ফোন নাম্বারঃ _____

শিক্ষাগত যোগ্যতাঃ _____

ধর্মঃ _____

পেশাঃ _____

বৈবাহিক অবস্থাঃ বিবাহিত অবিবাহিত তালাকপ্রাপ্ত
 বিচ্ছিন্ন বিধবা

শিশু (হ্যাঁ/না) যদি হ্যাঁ কতজনঃ _____

পারিবারিক ধরনঃ যৌথ একক

পরিবারে সদস্য সংখ্যাঃ _____

রোগীর সাথে সম্পর্কঃ _____

রোগীর আঘাতের সময়কালঃ _____

চিকিৎসার পর্যায়ঃ _____

যত্ন নেওয়ার সময়কালঃ _____

মাসিক আয়ঃ _____

আয়ের উৎসঃ _____

মাসিক খরচঃ _____

পরিবারের উপার্জনকারী সদস্যঃ _____

F-COPES (English Version)

FAMILY CRISIS ORIENTED PERSONAL EVALUATION SCALES

© Hamilton I. McCubbin David H. Olson Andrea S. Larsen

Purpose

The Family Crisis Oriented Personal Evaluation Scales is designed to record problem-solving, attitudes and behaviors which families develop to respond to problems or difficulties.

Directions

First, read the list of "Response Choices" one at a time. Second, decide how well each statement describes your attitudes and behavior in response to problems or difficulties. If the statement describes your response very well, then circle the number 5 indicating that you strongly agree; if the statement does not describe your response at all, then circle the number 1 indicating that you strongly disagree; if the statement describes your response to some degree, then select a number 2, 3, or 4 to indicate how much you agree or disagree with the statement about your response.

Please circle a number (1, 2, 3, 4, or 5) to match your response to each statement. Thank you.

When we face problems or difficulties in our family we respond by:	Strongly disagree	Moderately disagree	Neither agree nor disagree	Moderately agree	Strongly agree
1. Sharing our difficulties with relatives	1	2	3	4	5
2. Seeking encouragement and support from friends	1	2	3	4	5
3. Knowing we have the power to solve major problems	1	2	3	4	5
4. Seeking information and advice from person in other families who have faced the same or similar problems	1	2	3	4	5
5. Seeking advice from relatives (grandparents, etc.)	1	2	3	4	5
6. Seeking assistance from community agencies and programs designed to help families in our situation	1	2	3	4	5
7. Knowing that we have the strength with our own family to solve our problems	1	2	3	4	5
8. Receiving gifts and favors from neighbors (e.g., food, taking in mail, etc.)	1	2	3	4	5
9. Seeking information and advice from the family doctor	1	2	3	4	5
10. Asking neighbors for favors and assistance	1	2	3	4	5
11. Facing the problems "head-on" and trying to get solution right away	1	2	3	4	5
12. Watching television	1	2	3	4	5
13. Showing that we are strong	1	2	3	4	5
14. Attending church/ mosque/ temple	1	2	3	4	5
15. Accepting stressful events as a fact of life	1	2	3	4	5
16. Sharing concerns with close friends	1	2	3	4	5
17. Knowing luck plays a big part in how well we are able to solve family problems	1	2	3	4	5
18. Exercising with friends to stay fit and reduce tension	1	2	3	4	5

19. Accepting that difficulties occur unexpectedly	1	2	3	4	5
20. Doing things with relatives (get-together, dinners, etc.)	1	2	3	4	5
21. Seeking professional counseling and help for family difficulties	1	2	3	4	5
22. Believing we can handle our own problems	1	2	3	4	5
23. Participating in religious activities	1	2	3	4	5
24. Defining the family problem in a more positive way so that we do not become too discouraged	1	2	3	4	5
25. Asking relatives how they feel about problems we face	1	2	3	4	5
26. Feeling that no matter what we do to prepare, we will have difficulty handling problems	1	2	3	4	5
27. Seeking advice from a religious leader	1	2	3	4	5
28. Believing if we wait long enough, the problem will go away	1	2	3	4	5
29. Sharing problems with neighbors	1	2	3	4	5
30. Having faith in God	1	2	3	4	5

F-COPES (Bangla Version)

এফ- কোপস

(ফ্যামিলি ক্রাইসিস অরিয়েন্টেড পার্সোনাল ইভালুয়েশন স্কেল)

দিকনির্দেশ

প্রথমত, প্রতিক্রিয়া এর তালিকাটি এক এক করে পড়ুন। দ্বিতীয়ত, প্রতিটি বিবৃত সমস্যা বা সমস্যাগুলির প্রতিক্রিয়ায় আপনার মনোভাব এবং আচরণকে কতটা ভালভাবে বর্ণনা করে তা নির্ধারণ করুন। বিবৃতি আপনার প্রতিক্রিয়া খুব ভাল বর্ণনা করে, তাহলে আপনি দৃঢ়ভাবে সম্মত যে ইঙ্গিত সংখ্যা ৫ বৃত্ত করুন; যদি বিবৃতিটি আপনার প্রতিক্রিয়াটি একেবারেই বর্ণনা করে না, তাহলে সংখ্যা ১ বৃত্ত করুন যা নির্দেশ করে যে আপনি দৃঢ়ভাবে অসম্মতি জানান; যদি বিবৃতিটি আপনার কিছুটা প্রতিক্রিয়া বর্ণনা করে, তাহলে আপনার প্রতিক্রিয়া সম্পর্কে বিবৃতির সাথে আপনি কতটুকু একমত বা অসম্মত হন তা নির্দেশ করতে একটি সংখ্যা ২, ৩ বা ৪ নির্বাচন করুন।

অনুগ্রহ করে প্রতিটি বিবৃতিতে আপনার প্রতিক্রিয়া মিলে এমন একটি সংখ্যা (১, ২, ৩, ৪, বা ৫) বৃত্ত করুন। আপনাকে ধন্যবাদ।

পারিবারিক সমস্যা বা অসুবিধার সম্মুখীন হলে আমরা যে প্রতিক্রিয়া জানায়ঃ	দৃঢ়ভাবে অসম্মতি	পরিমিত-রূপে অসম্মতি	না সম্মতি না অসম্মতি	পরিমিত-রূপে সম্মতি	দৃঢ়ভাবে সম্মতি
১-আত্মীয়দের সাথে আমাদের কষ্টের কথা বলা।	১	২	৩	৪	৫
২-বন্ধুদের কাছে উৎসাহ ও সমর্থন চাওয়া।	১	২	৩	৪	৫
৩- বড় সমস্যা সমাধানের ক্ষমতা আমাদেরই আছে তা জানা।	১	২	৩	৪	৫
৪-অন্যান্য পরিবার যারা একই সমস্যার সম্মুখীন হয়েছে তাদের কাছে তথ্য এবং পরামর্শ চাওয়া।	১	২	৩	৪	৫
৫-আত্মীয়দের কাছে পরামর্শ চাওয়া (দাদা-দাদি ইত্যাদি)	১	২	৩	৪	৫
৬-আমাদের মত পরিস্থিতিতে থাকা পরিবারগুলিকে সাহায্য করে এমন কমিউনিটি এজেন্সি বা প্রোগ্রামগুলির কাছে সহায়তা চাওয়া।	১	২	৩	৪	৫
৭-আমাদের পরিবারের নিজেদের মধ্যেই সমস্যা সমাধানের ক্ষমতা রয়েছে সেটি জানা।	১	২	৩	৪	৫
৮-প্রতিবেশীদের কাছ থেকে উপহার এবং সহযোগিতা গ্রহণ করা (খাবার, চিঠি ইত্যাদি)।	১	২	৩	৪	৫
৯- পারিবারিক চিকিৎসকের কাছে তথ্য ও পরামর্শ নেওয়া।	১	২	৩	৪	৫
১০-প্রতিবেশীদের কাছে সাহায্য ও সহযোগিতা চাওয়া।	১	২	৩	৪	৫
১১-সরাসরি সমস্যার সম্মুখীন হওয়া এবং সমাধান বের করার চেষ্টা করা।	১	২	৩	৪	৫
১২- টেলিভিশন দেখা।	১	২	৩	৪	৫
১৩- নিজেদের শক্তিশালী দেখানো।	১	২	৩	৪	৫
১৪- গির্জা/মসজিদ/ মন্দির এ যাওয়া।	১	২	৩	৪	৫
১৫- বিষাদগ্রস্ত মুহূর্তকে জীবনের একটি অংশ হিসেবে গ্রহণ করা।	১	২	৩	৪	৫

১৬-বন্ধুদের নিকট সমস্যার কথা বলা।	১	২	৩	৪	৫
১৭-সমস্যা সমাধানের ক্ষেত্রে ভাগ্যের বড় ভূমিকা আছে সে সম্পর্কে জানা।	১	২	৩	৪	৫
১৮-শরীর সবল ও চিন্তা মুক্ত থাকতে বন্ধুদের সাথে ব্যায়াম করা।	১	২	৩	৪	৫
১৯-অসুবিধাগুলি যে অপ্রত্যাশিতভাবেই ঘটে তা মেনে নেওয়া।	১	২	৩	৪	৫
২০-আত্মীয়-স্বজনদের সাথে কাজ করা (সবাই একত্র হওয়া, রাতের খাবার খাওয়া, ইত্যাদি।	১	২	৩	৪	৫
২১-পারিবারিক সমস্যার জন্য পেশাদার কাউন্সেলিং এবং সাহায্য চাওয়া।	১	২	৩	৪	৫
২২- সমস্যা সমাধানে নিজেদের উপর বিশ্বাস রাখা।	১	২	৩	৪	৫
২৩- উপাসনালয়ে প্রার্থনায় অংশগ্রহণ করা।	১	২	৩	৪	৫
২৪-পারিবারিক সমস্যাগুলিকে আরও ইতিবাচক ভাবে দেখা যাতে আমরা নিরুৎসাহিত না হই।	১	২	৩	৪	৫
২৫-আত্মীয়দের জিজ্ঞাসা করা যে আমরা যে সমস্যার সম্মুখীন হই সে সম্পর্কে তারা কেমন অনুভব করে।	১	২	৩	৪	৫
২৬. এটা অনুভব করা যে, আমরা যতই প্রস্তুত থাকি না কেন, আমাদের সমস্যার সম্মুখীন হতে অসুবিধা হবে।	১	২	৩	৪	৫
২৭- একজন ধর্মীয় প্রধানের কাছে উপদেশ নেয়া।	১	২	৩	৪	৫
২৮- বিশ্বাস করি যে যদি আমরা অপেক্ষা করি তাহলে সমস্যা সমাধান হয়ে যাবে।	১	২	৩	৪	৫
২৯-প্রতিবেশীর সাথে সমস্যা আলোচনা করা।	১	২	৩	৪	৫
৩০- সৃষ্টিকর্তার উপর বিশ্বাস রাখা।	১	২	৩	৪	৫

Appendix D: Supervision Contact Schedule

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: Coping strategies and dealing with adversity of family members of patient with SCI

Name of student: Farida Rehman Adiba

Name and designation of thesis supervisor: Lutfun Nahar
 Lecturer in Occupational Therapy
 Department of Occupational Therapy

Appointment No	Date	Place	Topic of discussion	Duration (Minutes/ Hours)	Comments of student	Student's signature	Thesis supervisor signature
1	9.8.23	Teacher's room	Research title, aim, type of design	20mins	Got structured idea	Adiba	Lutfun Nahar
2	23.8.23	Teacher's room	Methodology, literature review	30mins	Got clear understanding and clear structure	Adiba	Lutfun Nahar
3	30.8.23	Teacher's room	Methodology, Scale, Title	30mins	Got clear feedback on scale selection and correction	Adiba	Lutfun Nahar

4	24.9.23	Teacher's room	Prevalence calculation	25 mins	Problem got solved	Adiba	
5	29.10.23	Teacher's room	Data collection process, Questionnaire	1 hour	Got structured guideline	Adiba	
6	2.12.23	Teacher's room	Population sampling, Author communication	1 hour	Got structured feedback	Adiba	
7	6.12.23	Teacher's room	Research proposal, Background & literature review	1 hour	Got correction	Adiba	
8	14.12.23	Teacher's room	Population response, Data collection guideline	45 mins	Gave update and problem solving	Adiba	
9	19.12.23	Teacher's room	Questionnaire discussion, Data management	1 hr	Got structured guideline	Adiba	
10	24.12.24	Library	SPSS data input	2 hr	Got work guideline	Adiba	
11	28.12.24	Library	confidence interval scoring instruction	1 hr	calculation problems	Adiba	
12	3.1.24	Library	Data input and variable	1 hr	Data input process	Adiba	
13	8.1.24	Library	Data analysis	30 mins	Data analysis procedure	Adiba	
14	13.1.24	Library	Data analysis	45 mins	Data related problem	Adiba	

15	17.1.24	Teacher's room	Result , discussion	1hr	got feedback on structure and correction	Adiba	Adiba
16	25.1.24	Teacher's room	1st draft feedback	2hr	correction of 1st draft	Adiba	Adiba
17	7.2.24	Teacher's room	Abstract, literature reviews , feedback	1hr	-how to correct and write abstract	Adiba	Adiba
18	17.3.24	Teacher's room	2nd draft feedback	1 hr	got feedback on aim, objective result, format	Adiba	Adiba
19	4.4.24	Teacher's room	Final draft feedback	2 hr	got feedback on final corrections	Adiba	Adiba
20	8.4.24	Teacher's room	Presentation reviews & feedback	1.5hrs	got feedback on structure & correction	Adiba	Adiba

Note:

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