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Knowledge, Experience and Burden of the Attendant Who Have Experience to Manage Tetraplegic SCI Patients Attended at CRP

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We the undersigned certify that we have carefully read & recommend to the Faculty of Medicine, University of Dhaka, for the acceptance of this dissertation entitled

Knowledge, Experience and Burden of the Attendant Who Have Experience to Manage Tetraplegic SCI Patients Attended at CRP

Submitted by **Jannatul Ferdous Purba** for the partial fulfillment of the requirement for the degree of Bachelor of Science in Physiotherapy (B.Sc. PT).

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Declaration

I declare that the work presented here is my own. All sources used have been cited appropriately. Any mistakes or inaccuracies are my own. I also declare that for any publication, presentation or dissemination of information of the study, I would be bound to take written consent from the Department of Physiotherapy, Bangladesh Health Professions Institute.

Signature: **Date:**

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List of acronyms

BHPI	Bangladesh Health Professions Institute
SCI	Spinal cord injury
IRB	Institutional Review Board
CRP	Centre for the Rehabilitation of the Paralysed
QoL	Quality of life
LBP	Low back pain
GH	General health
GAD	Generalized anxiety Disorder
PHQ	Patients Health Questionnaire
ZBI	Zarit Burden Interview
VAS	Visual Analogue Scale
MH	Mental Health
PF	Physical functioning
SCI	Spinal Cord Injury
SPSS	Statistical Package for the Social Sciences
WHO	World Health Organization
UK	United Kingdom
USA	United State of America

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Abstract

Purpose: The purpose of this study was to assess the knowledge, experience and burden of the attendances who are experienced to manage tetraplegic SCI patients. **Objectives:** To detect the knowledge, experience and burden reported by tetraplegic patient's attendance who are attendant at CRP. **Methods:** The cross-sectional study was chosen to carry out this study among 42 participants who were selected according to inclusion criteria from May 2022 to July 2022. All data were collected through a standard structured questionnaire having socio demographic, PHQ questionnaire, The Visual analogue scale (VAS), Generalized Anxiety Disorder (GAD) Scale, Zarit Burden Interview (ZBI) scale, this used to assess pain, depression, anxiety and burden among 42 participants. The inferential statistical has been calculated by chi-square test. Statistical Package for Social Science (SPSS version 20) was used for data analysis **Results:** Among 42 of the participants their overall age mean was 1.43 and SD was 0.547. Among them 100% participants suffer from LBP, 60% suffer from severe pain and 40% suffer from moderate pain.83.3% had moderate anxiety, 14.3% had severe anxiety and 2.4% had mild anxiety. 38.1% of the participants had severe depression, 45.2% had moderately severe depression, 16.7% had moderate depression. 78.6% of the participants had high burden, 21.4% had mild to moderate burden. Statistically significant association also found in between some socio- demographic information and VAS score, GAD-7 score, PHQ-9 score and ZBI score. such as age and VAS ($P<0.002$), occupation and GAD ($P<0.05$), gender and ZBI ($P<0.03$), occupation and PHQ ($P<0.01$), VAS score and PHQ score ($P<0.01$).In this study the participant's knowledge about caregiving was relatively good but physical health, mental health, social quality of life was poor. **Conclusion:** The research highlights that carers assume their roles in early-middle age and may persist as primary carers for several decades. The results of the study suggest that low back pain, depression and anxiety are commonly experienced during caregiving a long period of time. Female attendants are more suffer from LBP severity during managing the patients. Physical health and mental health may worse over time that's why attendant felt a huge burden in their life. It not only affects the attendant's life but also affect patients life as well as their prognosis.

***Key words*:** *Knowledge, Low back pain, Anxiety, Depression, Burden.*

CHAPTER I INTRODUCTION

1.1 Background

Bangladesh is a developing country that has a dense population. Near about 10% of total population are disable in Bangladesh where 43% are physically disable (Haque, 2012). Bangladesh has poor occupational safety measures, roads and mixed traffic, with vehicle users unwilling to use seat-belts. This makes the population vulnerable to Spinal Cord Injury (Razzak et al., 2017). Spinal cord injury (SCI) is a most common injury that is medically complex and also a life-disrupting condition (World Health Organization, 2013).

A spinal cord injury (SCI) is an insult to the spinal cord that causes a change in its normal motor, sensory, or autonomic function, which can be temporary or permanent. Damage to the spinal cord has profound and global effects. SCI can also affect the functioning of the sensory, respiratory, cardiovascular, gastrointestinal, genitourinary, and integumentary system (Somers, 2018).

The inability to move the upper and lower limbs easily is referred to as tetraplegia (sometimes known as quadriplegia). The fingers, hands, arms, chest, legs, feet, and toes are the most commonly affected areas, while the head, neck, and shoulder may also be affected (Chin et al., 2018).

Spinal Cord Injury mostly occurs due to trauma. Traumatic spinal cord injury (TSCI) causes partial or complete loss of motor, sensory and autonomic function below the neurological level of the injury in which the neural tissue within the spinal canal is damaged by an external force. Traumatic Spinal Cord Injury is related with long-lasting disabilities and centrals to recurrent complications that have significant impacts on personal life and the health care system (Koskinen, 2015).

The World Health Organization (WHO) estimates that somewhere in the world, between 250000 and 500000 people experience a spinal cord injury each year. A catastrophic condition that affects 12.1–57.8 people per million year is spinal cord injury (SCI) (Rahimi-Movaghar et al., 2013). Approximately 300 people with severe spinal cord

injuries are admitted to an Australian spinal cord injury unit (SCI) each year (Middleton et al., 2012).

SCI incidence in Bangladesh has been calculated as 2.5 cases per million people (Hoque et al., 2002). Each year, the CRP receives admission of about 390 patients who have recently suffered spinal cord injuries (CRP, 2010). About 20000 new spinal cord injury cases are reported each year in India. When the thoracic, lumbar, or sacral roots of the spinal cord are injured, both lower limbs and all or portion of the trunk are completely or partially paralyzed (Singh et al., 2013).

Patients with SCI should expect to live longer than those with other degenerative diseases. Caretakers of people with SCI must therefore spend a lot of time to provide for the patient. Numerous studies have shown that this illness may cause a variety of issues for the primary carers and/or spouses of SCI survivors. There is comparatively little research in the literature on the quality of life for main carers of SCI survivors. SCI greatly reduces the quality of life of the caregiver, regardless of how severe the disability is (Unalan et al., 2011).

The term "quality of life" refers to a person's satisfaction, which may be influenced by their handicap and includes their health, relationships, emotional, social, and physical function as well as happiness and satisfaction with their living situation and financial situation (Manns and Chad, 2019).

Because individual differences in health status and health-related quality of life (HRQoL) might result from various medical conditions, these factors are crucial (Andresen et al., 2009). Age, level of education, neurologic condition, employment, functional status, presence of comorbidities, etc. of the patient have an impact on their quality of life (Gurcay et al., 2010). However, the increase of functional independence and quality of life is primarily a result of lifestyle choices and physical activity (Kawanishi and Greguol, 2013).

Caregiving is a multifaceted activity which requires knowledge and skills especially in case of tetraplegia, that is conditions involving multiple morbidities and self-management requirements (Hor and Tylor 2010). Long-term caregiving may have an impact on the

caregivers' physical, mental, and social health as well as their wellbeing, marriage, employment, and financial situation (Davis et al. 2009; Yilmaz, Erkin & Ezke 2013). These extra worries could eventually result in the caregivers' health and health-related quality of life (HRQoL) declining. Caretakers experienced musculoskeletal issues, anxiety, depression, and decreased life satisfaction as a result of inadequate training and awareness, which was linked to ADL (Nelson et al.,2008). They face various physical and psychological issues while providing care because tetraplegic patients completely depend on their caregiver in their daily routines, such as bathing, using the restroom, and other personal care (Berker et al., 2011).

Numerous studies have demonstrated that parents experience more stress than other caretakers of different diseases. The carers are put under financial, bodily, and emotional strain as a result of this increased stress. Numerous research have shown that SCI carers suffer lower health-related quality of life and higher levels of worry, sadness, and stress. The carers experience physical stress in addition to psychological stress . The caretakers are in charge of things like personal hygiene, assistance with movement, and carrying out exercises at home. Musculoskeletal system issues consequently become common and difficult health issues for the caretakers. Numerous research have looked into the issues with the musculoskeletal system and associated aspects in those who care for tetraplegic SCI patients (Kawanishi and Greguol, 2013).

1.2 Rationale of the study

SCI is a common problem in our country and it will increase day by day. SCI affects a large number of young individuals with a significant cost to affected persons, families and societies both in terms in economic and non economic cost. Damage to the spinal cord has profound and global effect (Somers, 2010). Today, spinal cord damage is a major concern. The incidence rate is increasing aggressively day after day.

Tetraplegic patients are completely dependent on their caregivers to do their ADLs since they are unable to move their upper and lower limbs on their own. As a result, these caregivers frequently have physical, psychological, and financial difficulties.

Caregiving is a multifaceted activity which requires knowledge and skills especially in case of tetraplegia , that is conditions involving multiple morbidities and self-management requirements. Informal caregivers play a significant part in helping patients with SCI. They went through several changes in every aspect of their lives as a result of a lack of appropriate information, training, resources (psychological, social, and financial), and knowledge. Musculoskeletal issues in the caregiver may have a negative impact on the patient's rehabilitation. However, a healthy caregiver supports the patient's motivation, functional result, and effective rehabilitation.

Numerous psychological and physiological elements have an impact on the attendance attitude, which can lead to depression and anxiety. Depression and anxiety have been discovered to have a significant impact on health; as a result, it can make people less motivated to seek therapy and other forms of treatment, which might hinder efforts to improve quality of life. Losing motivation as a result of sadness, worry, and a sense of burden is the likely effect, and it is to blame for attendees' uncertain, fruitless, and problematic lives. The knowledge, experience, and hardship of attendances with SCI will be made known to physiotherapists and other specialists through this study, and it may help in finding a solution.

1.3 Research Questions:

What are the Knowledge, Experience and Burden of the Attendants Who Have Experience to Manage Tetraplegic SCI Patients Attended at CRP?

1.4 Study Objective

1.4.1 General Objective:

To detect the knowledge, experience and burden reported by tetraplegic patient's attendance who are attendant at CRP.

1.4..2 Specific Objectives:

1. To identify the socio demographic characteristics of the participants.

2. To find out their thinking and knowledge about SCI.

3. To assess their physical and mental experience which is faced by caregiver in everyday life.

4. To detect the burden about tetraplegic SCI patients.

5. To evaluate the limitation of activities of the participants.

1.5 Operational Definitions: Spinal cord injury (SCI): It is the term used to describe the loss of sensory and motor function that results when the spinal cord is damaged for any reason, including trauma or disease.

Paraplegia: A condition in which the lower body, including both legs, is paralyzed.

Tetraplegia: Loss of strength in all four extremities due to damage to the cervical part of the spinal cord.

Paralysis: Injury or illness to the neurological system can impair a person's capacity to move a specific bodily part, which is known as paralysis. Paralysis is the term for this reduced motor function.

Depression: Major depressive disorder, sometimes known as depression, is a serious medical condition that frequently affects people's feelings, thoughts, and behaviors.

Anxiety: Anxiety is a mental condition characterized by tense emotions, worry-inducing thoughts, and bodily changes including increased blood pressure. The hallmark of anxiety disorders is the recurrence of intrusive thoughts or worries. They could steer clear of specific situations out of worry. There may also be physical signs including sweating, shaking, dizziness, or a fast heartbeat.

Burden: Something that is extremely challenging to accept, do, or deal with.

CHAPTER II LITERATURE REVIEW

Spinal cord injury (SCI) is a dangerous and disabling disorder that affects between 27.11 and 77.0 people per million in the United States each year, resulting in 12,000 to 20,000 new cases. (Scivoletto et al.,2023) found that Young patients suffer the most traumatic SCIs, while people 65 years of age or older account for 20% of all SCI cases. Traumatic SCI affects between 3.6 and 195.4 persons per million people worldwide. Early functional outcome prediction of the patient after traumatic SCI is essential to inform care choices that may reduce expenses while also giving the patient and family a better understanding of long-term expectations.

The prognosis of impairments, disabilities, and handicaps should be clear in order to develop successful rehabilitation programs built on realistic goals. The neurological prognosis following SCI has received a lot of attention recently. Based on the severity of the initial damage, the motor and sensory recovery after severe SCI has been quantified in many investigations. Within the first six months following injury, the majority of the motor recovery takes place. The level and extent of the lesion determines the degree of functional improvement, which is more important in determining the success of rehabilitation (Schonherr et al., 2018).

The primary cause of mortality and morbidity, the life-altering event that has an impact not only on patients with SCI but also on their spouses, parents, siblings, and children morbidity (Ali & Tawfiq, 2013). High levels of individual disability brought on by spinal cord injury result in drastic changes in lifestyle (Kawanishi and Greguol, 2013). Spinal cord injury patients' life expectancy was significantly shorter in developing nations like Bangladesh than in wealthy nations (Razzak et al., 2011).

Trauma to the spinal cord is the primary cause of the prevalent malfunctioning of the spinal segments. Traumatic and non-traumatic events can both result in spinal cord injury. In Bangladesh, spinal cord injuries can occur for a variety of reasons. The most frequent causes include falling from a height, motor vehicle accidents, tripping while carrying a

large object on the head or back, bull attack, gunshot wound, physical assault, disease process, diving in shallow water, and others (Ekman, 2012).

Recent research (Kong et al., 2022) indicates that acute spinal cord injury, which results in secondary damage by causing inflammation, ischemia, and toxicity, causes primary nerve injury. After SCI, there is a motor control deficit that interferes with daily tasks (Rahman et al., 2012). One of the debilitating conditions is SCI, which results in limb paralysis and injury such as compression, contusion, or laceration disrupts autonomic function at the site of injury or below. Depending on the level of the lesion, permanent disability can include paralysis, loss of sensation, neuropathic pain, etc (Mothe & Tator, 2013).

Spinal cord injury or damage can cause a wide range of impairments, activity limitations and participation restrictions which has an adverse impact on the society (New et al., 2013). Nwankwo & Uche (2013) found that in SCI Males are more frequently injured than females (4.3:1), and injuries to the cervical, thoracic, and lumber spines account for 53% of all injuries among people aged 31 to 45. The annual incidence of traumatic SCI in the United States is 40 incidences per million, or 1200 new cases each year (Rabadi et al., 2013). In Australia, males are affected by non-traumatic SCI at a ratio of 197:169, and paraplegia is more common than tetraplegia (98 per million) with a prevalence of roughly 269 per million) (New et al., 2013). The incidence of SCI is 10.4 and 83 per million people worldwide every year, with a mean age of 33, a male to female ratio of 3.8:1, and one-third of patients being tetraplegic globally (Wyndaele & Wyndaele, 2006). And 2.5 million people live with SCI around the world (Oyinbo, 2011).

In CRP, Bangladesh, people between the ages of 25 and 29 are most frequently affected; males are affected more frequently than females (83% to 92%; 92% rural; 8% urban); the majority of patients have paraplegia (56%; 44% of cases had cervical lesions). Men are more susceptible to spinal cord injury than women, and the most common causes are falls and motor vehicle collisions (MVCs), which account for 27% and 29% of all traumatic spinal cord injuries, respectively. In Asia, the incidence rates of SCI range from 12.06 to 61.6 per million, with an average age of 26.8 to 56.6 years (Islam et al., 2011).

The most frequent among catastrophic injuries is spinal cord injury, which anyone can suffer from. Compared to other age groups, young adults suffer from lifelong disability more frequently. Seventy-five percent of spinal cord injuries happen to people under the age of 45, and fifty-four percent happen to those between the ages of 16 and 30 (Winslow & Rozovsky, 2003). Typically, spinal cord damage affects men more than women. Complete injuries strike younger men more than older people or women. According to a study, there are numerous factors that might lead to SCI, including driving (36.5%), falling (28.5%), violence (14.3%), sports (9.2%), and other reasons (11.4%). 80.7% of the rate is affected. Since 2010, the average age of this injury has been 46 (Carlson & Gorden, 2012).

Trauma, whether direct or indirect, can result in traumatic spinal cord injury. There are three main reasons why patients are hospitalized to hospitals in underdeveloped nations. They are being struck by an object, falling from a great height, and transportation accidents. According to a study, 561 people suffered severe spinal cord injuries between 2001 and 2010. Beijing's annual incidence rate is higher than that of other nations and regions at 60.6 per million. Depending on the level of the lesion, TSCI patients may experience a variety of disorders, including stiffness, sensory abnormalities, and excessive reflex behaviors (Carlson & Gorden, 2012).

The spinal cord begins as a continuation of the medulla oblongata; the caudal part of the brainstem (Moore & Dalley, 2006). The term "spinal cord injury" (SCI) refers to a spinal cord insult that alters the spinal cord's normal motor, sensory, or autonomic function. These changes can be temporary or permanent (International Standards for Neurological Classifications of Spinal Cord Injury, 2000). Incomplete injuries are those in which there is only a partial preservation of sensory and/or motor functions below the level of the nervous system, which includes the lowest portion of the sacrum (Hossain et al., 2008). According to a different study, insufficient services, poverty, unfavorable attitudes toward people with SCI in society, unfair legislation, an inaccessible built environment, and inefficient transportation networks are the key factors contributing to people with SCI's poor integration into society life (Lysack et al., 2007).

The grading of SCI severity is based on the American Spinal Injury Association's (ASIA) disability scale as follows:A (complete): The sacral segments have lost all motor and sensory function. S4-S5. B (incomplete): The sacral segment S4-S5 is included, and sensory but not motor function is preserved below the neurological level. C (incomplete): Below the neurological level, motor function is intact, and more than half of the major muscles have a muscle grade of below 3. E (normal): Sensory and motor abilities are healthy. Tetraplegia caused by injuries to the C4, C6, T6, and L1; paraplegia caused by injuries to the T6 and L1 (Thuret et al., 2006).

Only 16.4% of the sample population in Bangladesh lived for 10 years, which is substantially lower than in affluent nations like Finland (97.9%), Australia (86%), Canada (92%), the United Kingdom (85%), and the United States (80.7%), according to a 10-year study on the life expectancy of people with SCI. In addition, the study discovered that Bangladesh's situation is worse than that of other developing nations. The information shows that spinal cord injury survivors in Bangladesh have very little access to safe and worthwhile medical care. The study also identified a few potential reasons why people with SCI had a shorter life expectancy, such as poor acute care and inadequate social reintegration (Razzak et al., 2011).

Taking care of an ill or elderly person is what a caregiver does, according to the Oxford Advanced Learner's Dictionary (2001). However, the severity of the damage does not seem to have a greater impact on them, and primary caregivers typically have to care for a person with SCI for a very long time. According to other studies, the quality of life of primary caregivers of a spinal cord injured victim is considerably harmed. This is due to the fact that people with SCI have a longer expected lifespan than people with other chronic diseases like Alzheimer's or AIDS. Caretakers of patients with SCI endure more suffering than other carers do (Unalan et al., 2011).

A related study discovered that female caregivers of children with mental health issues were more likely to experience caregiver anxiety and sadness. Additionally, caregiver melancholy was less likely to occur if the kid was older at the time of the accident. Anxiety and depression were predicted by having poor social connections, a caregiver

with mental health issues, and a caregiver who was less educated than the child (Kelly et al., 2011).

The person who is primarily involved in the patient's care and provides the most support and/or assistance" is referred to as the primary caregiver (Blanes et al., 2007). Nowadays in developed countries as well as worldwide Spinal Cord Injury (SCI) remains a major public health issue. A significant increase of incidence of the SCI has been 13 observed due to the increase of road traffic accidents (Notara et al., 2012).). According to literature 2.5 million people are affected worldwide by SCI (Thuret et al., 2006). The most frequent catastrophic injuries are spinal cord injury. Young individuals are more likely than people of other ages to experience a lifelong handicap due to SCI. 54% of SCI occur in people between the ages of 16 and 30. Those under 45 years old account for 75% of injuries (Winslow and Rozovsky, 2003). As a result of recent advances in medical technology, persons surviving a spinal cord injury (SCI) are living longer, and often require varied degrees of assistance over their life span (Ebrahimzadeh et al., 2014). People with SCI may have to live with their impairment for a lot longer till the end of their natural lives due to improved survival rates and life spans (Lee, 2000). People with SCI frequently suffer considerable functional limits and lack of independence, depending on the severity of their impairment (Notara et al., 2012).

Biomechanical studies have shown that heavy lifting by caregivers, typically done with a bent or twisted posture, frequently results in severe spinal stress. Experimental research has linked these risk variables to the emergence of spinal tissue damage (Warming et al., 2009). A person's perception of his or her own quality of life can be influenced by a variety of factors, including physical, psychological, and social functioning, the ability to work, relationships with others in the community, and others. Quality of life is a multidimensional concept (Kreuter et al., 2005). Quality of life is described as "individuals' perception of their position in life, in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards, and concerns" by the World Health Organization (Kawanishi & Greguol, 2013).

An individual's view of his or her place in society and their aspirations for their life in

relation to the culture and value systems in which they reside are considered to constitute the individual's quality of life (QoL) (Munce et al., 2013). Measurement of quality of life can provide information regarding health states beyond diagnosis, the effects of disease and its care on several facets of life (Geyh et al., 2010). In this aspect, spinal cord injuries continue to be disregarded because there is a lack of information and resources available for SCI patients. SCI has consequently grown to be a significant public health issue in Bangladesh. And today, careful consideration is required for every public health issue. The most important health metric is life expectancy (Osman, 2010).

According to a recent study, people with spinal cord injuries have historically had low life expectancies. According to the study, those with SCI had 10–12 times shorter life expectancies than the general population. The same study found that Bangladesh's insufficient acute care of SCI patients was a significant cause of death. Poor quality of life (QoL) for family members and carers results from poor social acceptance and inadequate re-integration into the community once the patient is released from the hospital (Razzak et al., 2011). In recent literature it has been found that spouses of persons with SCI may suffer higher levels of stress than the other family members in taking up the care-giving role where three main factors are identified as strongly associated with adjustment outcomes and these are coping strategies, locus of control, and social support though, these are all Western-based studies where people from different cultures may have different sources of stress and corresponding coping patterns and traditionally, Chinese are consi dered to be group-oriented, or more specifically, family-oriented and socially dependent people and where each party of the relationship is expected to perform their role according to the norms and failure to achieve these role dualities will lead to discrimination by the others others (Chan, 2020).

CHAPTER III METHODOLOGY

3.1. Study Design

A cross-sectional descriptive study was performed with structured questionnaires and interviews were conducted with primary caregivers of persons with Tetraplegic spinal cord injury (SCI).

3.2 Study site

CRP is the biggest hospital and renowned rehabilitation centre for Spinal Cord Injury (SCI) among South Asia. Almost 100 Spinal Cord Injured patients are admitted at CRP in same time. For this reason the researcher had to collect data within short time to maintain the contrasts of course module time. Spinal Cord Unit of CRP was chosen as the venue to collecting the data. So CRP is the best setting for study & it reflected the entire population**.**

3.3 Study population

All attendants of Tetraplegic patients' who are admitted at CRP for receiving treatment service at SCI unit.

3.4 Sample size

$$\mathbf{N}=\frac{z2pq}{d2}$$

Here,

Z (confidence interval) = 1.96
P (prevalence) =10% =50%
And, Q = 1-.5
=.5

$$N = \frac{1.96^2(0.1)(1-0.5)}{(0.05)2}$$

=384

In this project study, the researcher selected 42 caregivers of Tetraplegic spinal cord injury patient from the spinal cord injury unit of CRP through convenience sampling technique. The investigator aimed to focus his study by 384 samples following the calculation regarding SCI patients. Due to time limitation the researcher has to choose 42

participants to conduct this study from May- July; within the short time it could not be possible to conduct the study with a large number sample.

3.4 Sampling technique

Sampling refers to the process of selecting the subjects or individual. The researcher was selected convenience sampling technique due to small size of population.

3.5 Inclusion criteria

3.5.1 Tetraplegic SCI patient's carers

3.5.2 Primary caregivers

3.5.3 Both male and female

3.6 Exclusion Criteria

- Paraplegic patient's caregiver
- Secondary caregivers
- Carers with cognitive problems
- Irregular caregivers (less than 4 weeks)

3.7 Data collection tool :

3.7.1 Pen

3.7.2 Pencil

3.7.3 White paper

3.7.4 Clip board

3.7.5 Calculator

3.7.6 Sociodemographic questions

3.7.7 Generalized Anxiety Disorder (GAD-7) scale

3.7.8 Patients Health Questionnaire (PHQ) scale

3.7.9 Zarit Burden Interview (ZBI) scale

Generalized Anxiety Disorder (GAD-7) scale : It is a seven-items instrument that is used to measure or assess the severity of generalized anxiety disorder (GAD).Scores of 5,10 and 15 are taken as the cut off points for mild, moderate and

severe anxiety respectively. When used as a screening tool, further evaluation is recommended when the score is 10 or greater. Using the threshold score of 10, the GAD-7 has a sensitivity of 89% and a specificity of 82% for GAD.

Patient Health Questionnaire (PHQ-9) : It is a multipurpose instrument for screening, diagnosing and monitoring the severity of depression. It is a reliable and valid measure of depression severity.PHQ-9 has a sensitivity of 88% and specificity of 88% for major depression.

Zarit Burden Interview (ZBI) Scale : ZBI is used to assess subjectively experienced burden by caregivers to chronically disabled persons. There is a three levels of burden . No or little burden (0-20 points), moderate burden (21-40 points) and severe burden (>40 points).

VAS Scale : It is used to measure the pain sensitivity. The VAS consists of a 10 cm line, with two end points representing 0 (no pian) and 10 (worse pain). Ask the patients to rate their current level of pain by placing the mark on the line.

3.9.1 Method of data collection :The questions will be asked in face to face interviews. It is useful because this technique ensures that the researcher will obtain all the information required, while at the same time it gives the participants freedom to respond and illustrated concepts.

3.9.2 Questionnaire

• For data collection, the researcher will use a close-ended structured questionnaire.

• The Knowledge, experience, burden were assessed by self made questionnaire, VAS scale, GAD-7 scale, PHQ-9 scale, ZBI questionnaire.

• For data collection, a Bengali questionnaire was used so that the carers will understand the questionnaire in the easiest way.

3.9.3 Duration of data collection

Data was collected carefully and confidentiality and maintained all ethical considerations. The researcher gave each participant a particular time to collect the data. Each questionnaire took approximately 20-25 minutes to complete.

3.9.4 Procedure of data collection

Data was collected by the researcher himself. The questionnaire was completed or filled up in front of the researcher.

3.9.5 Data analysis procedure

Data will be analyzed in Microsoft office Excel 2010 using a SPSS 20 version software program.

3.10 Ethical consideration

- Researcher will follow the Bangladesh medical research council (BMRC) guide line WHO research guide line.
- This protocol presentation was firstly submitted to the Institutional Review Board (IRB) of BHPI and initial permission was taken.
- Permission was taken from the Head of the Department of Physiotherapy, BHPI and head of the Department of Physiotherapy, CRP before data collection.
- Permission was takem from the In-Charge of SCI Unit, CRP for data collection from the patients.
- Researcher will maintain the confidentiality of the collected data from the individuals.
- All the participants and the authority were informed about the purpose of the study.
- Researcher ensures the confidentially of participants and share the information only with research supervisor.

3.11 Informed consent

Written consent (appendix) was given to all participants prior to completion of the questionnaire. The researcher explained to the participants about his or her role in this study and aim and objective of this study. The researcher received a written consent from every participants including signature. So the participant assured that they could understand about the consent from and their participation was on voluntary basic. The participants were informed clearly that their information would be kept confidential. The researcher assured the participants that the study would not be harmful to them. It was explained that there might not a direct benefit from the study for the participants but in the future cases like them might be get benefit from it. The participants had the rights to withdraw consent and discontinue participation at any time without prejudice to present or future care at the spinal cord injury (SCI) unit of CRP. Information from this study was anonymously coded to ensure confidentiality and was not personally identified in any publication containing the result of this study

3.12 Rigor of the study

The rigorous manner was maintained to conduct the study. The study was conducted in a clean and systemic way. During the data collection it was ensured participants were not influenced was experiences. The answer was accepted whether they were negative or positive impression no leading questions were asked or no important questions were avoided. The participant information was coded accurately and checked by the supervisor to eliminate any possible errors. The entire information was handled with confidentiality. In the result section, outcome was not influenced by showing any personal interpretation. During conduct the study every section of the study is checked and rechecked by the research supervisor.

CHAPTER IV RESULT

Socio demographic information

4.1.1 Age of the participants:

Out of the 42 participants, the minimum age 15 years, maximum age 65 years, the mean of the age is 1.43 and the standard deviation is 0.547 persons was participant in this study. In this case of age the most participants was attended from 15-35 age group 58.1% (n=25). Among 42 of the participants 37.2% (n=16) participants were in 36-55 age group, 2.3% (n=1) participants were in 56-75 age group.

Table 1: Age group of the participants

Age group	Frequency (N)	Percent%
15-35	25	58.1%
36-55	16	37.2%
56-75	1	2.3%
Total	42	100.0%

4.1.2 Gender of the participants

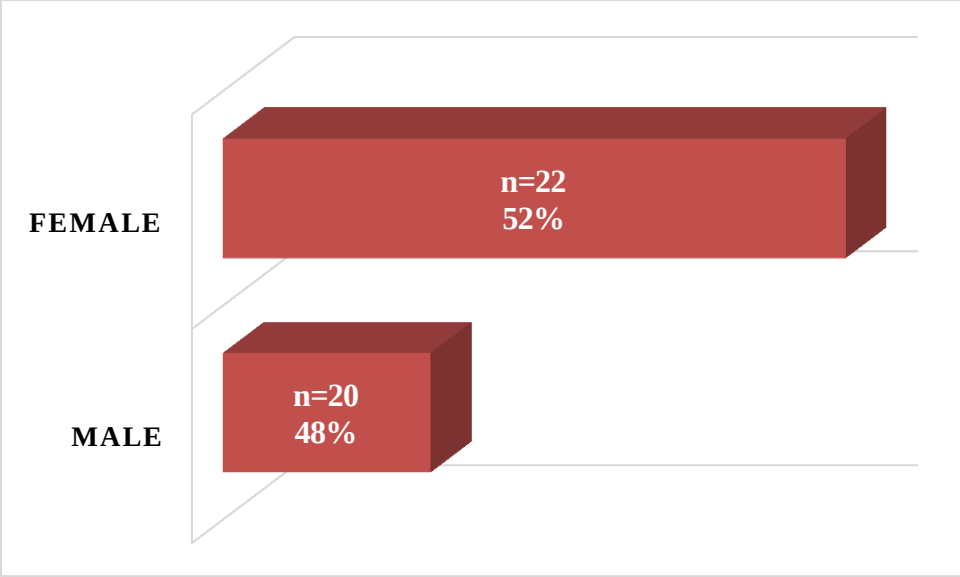

Figure 1: Gender of the participants

Among 42 participants, the most participants were male. Data showed 48% (n=20) was male and 52% (n=22) was female.

4.1.3. Residential area of the participants

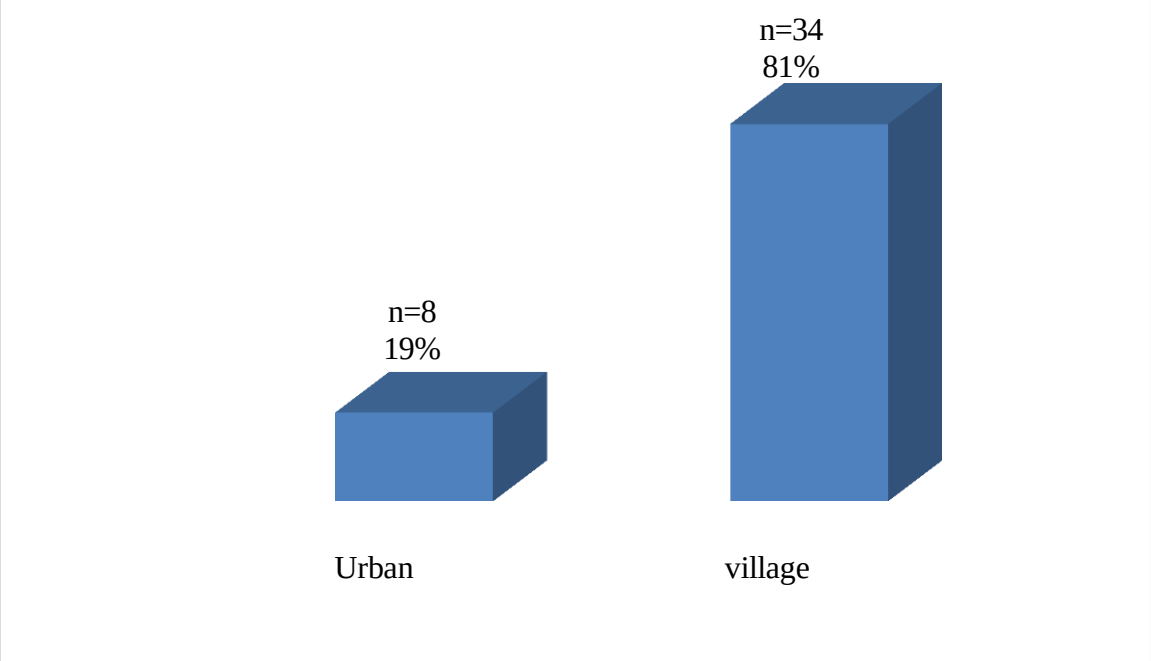

Figure 2: Residential area of the participants

Among 42 participants 81% (n=34) lived in village areas and 19% (n=8) lived in urban area.

4.1.4. Educational level of the participants

In this study, educational level of the participants 16.3% (n=7) were uneducated, 27.9% (n=12) were primary, 43% (n=18) participants had secondary education , 7% (n=3) participants got higher secondary education , 4.7%(n=2) were graduated.

Table 02 : Educational level of the participant

Educational level	Frequency (N)	Percent %
Uneducated	7	16.3%
Primary	12	27.9%
Secondary	18	43%
Higher secondary	3	7%
Graduated	2	4.7%
Total	42	100.0%

4.1.5. Occupation of the participants:

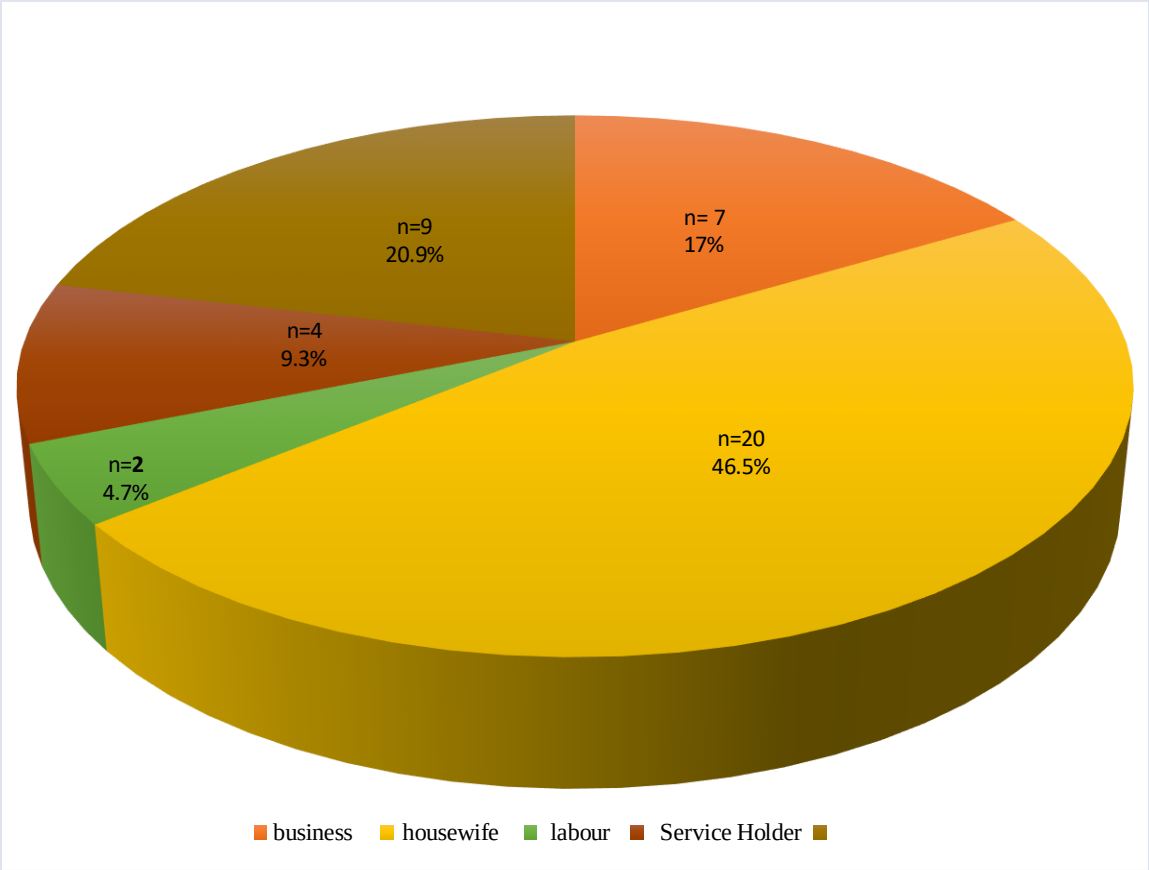

Figure 3: Occupation of the participants

In this study, occupation of the participants 17%(n=7) were businessman , 9.3%(n=4) were service holder , 4.7% (n=2) were day labour, 46.5%(n=20) were housewife , 20.9%(n=9) were student.

4.1.6. Monthly income of the participants :

Out of 42 participants, the maximum income is 22000, minimum is 10000. In this study most of the participant's income range from 10000-15000 group 39.5% (n=17), among 42of participant's income 14% (n=6) in 15001-20000 group and 2.3% (n=1) in 20001-25000 group.

Table 03 : Monthly income of the participants

Monthly income	Frequency (N)	Percent%
10000-15000	17	39.5%
15001-20000	6	14%
20001-25000	1	2.3%
Total	42	100.0%

4.1.7 Marital status of the participants

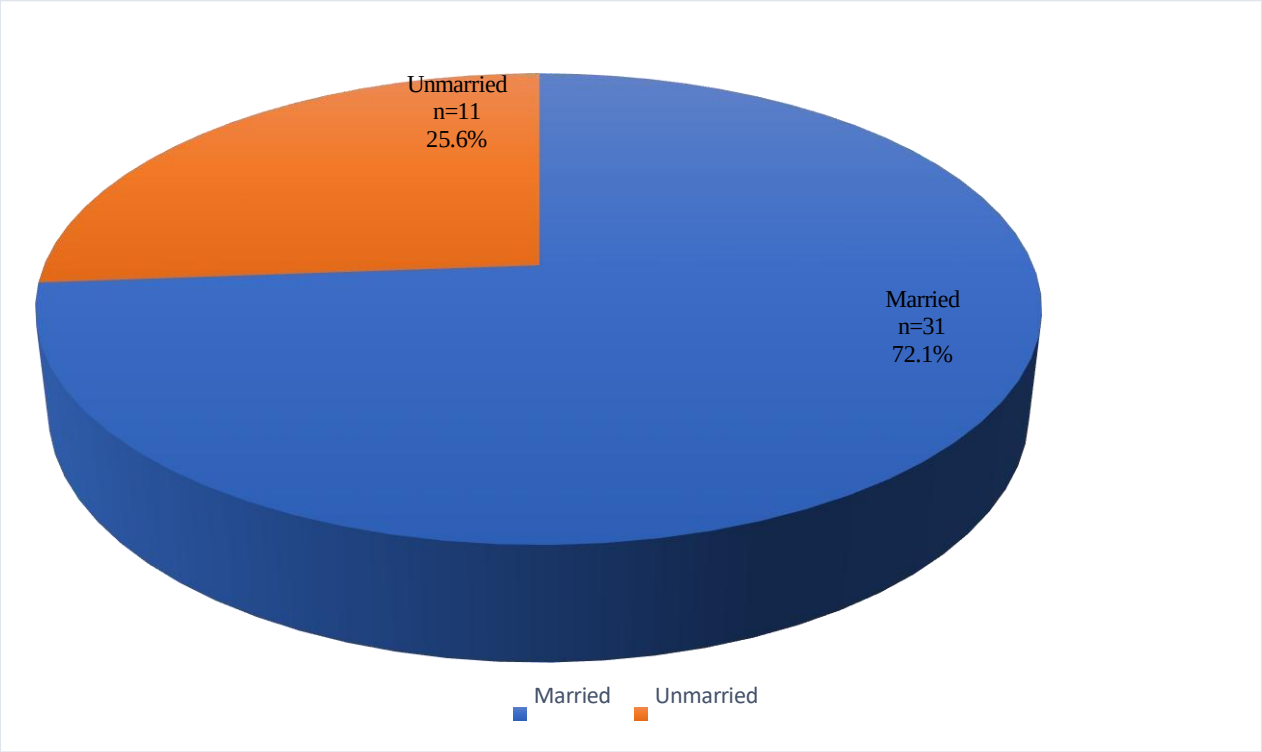

Figure 4: Marital status of the participants

Among 42 participants, most participants were married. Data showed that 72.1% (n=31) were married, 25.6% (n=11) were unmarried.

4.1.8. Relationship of participant with patient

In this study participant's relationship with patient is 23.3% (n=10) were son, 5% (n=2) were daughter, 14.0% (n=6) were father, 32.6% (n=13) were wife, 7.0% (n=3) were husband, 16.3% (n=7) were mother, 2.3%(n=1) were brother.

Table 04: Relationship of participant with patient

Relation with patient	Frequency (N)	Percent %
Mother	10	23.3
Daughter	2	5
Father	6	14.0
Wife	13	32.6
Husband	3	7.0
Son	7	16.3
Brother	1	2.3
Total	42	100%

4.2. Knowledge about patient care :
4.2.1. Take care of skin of patient :

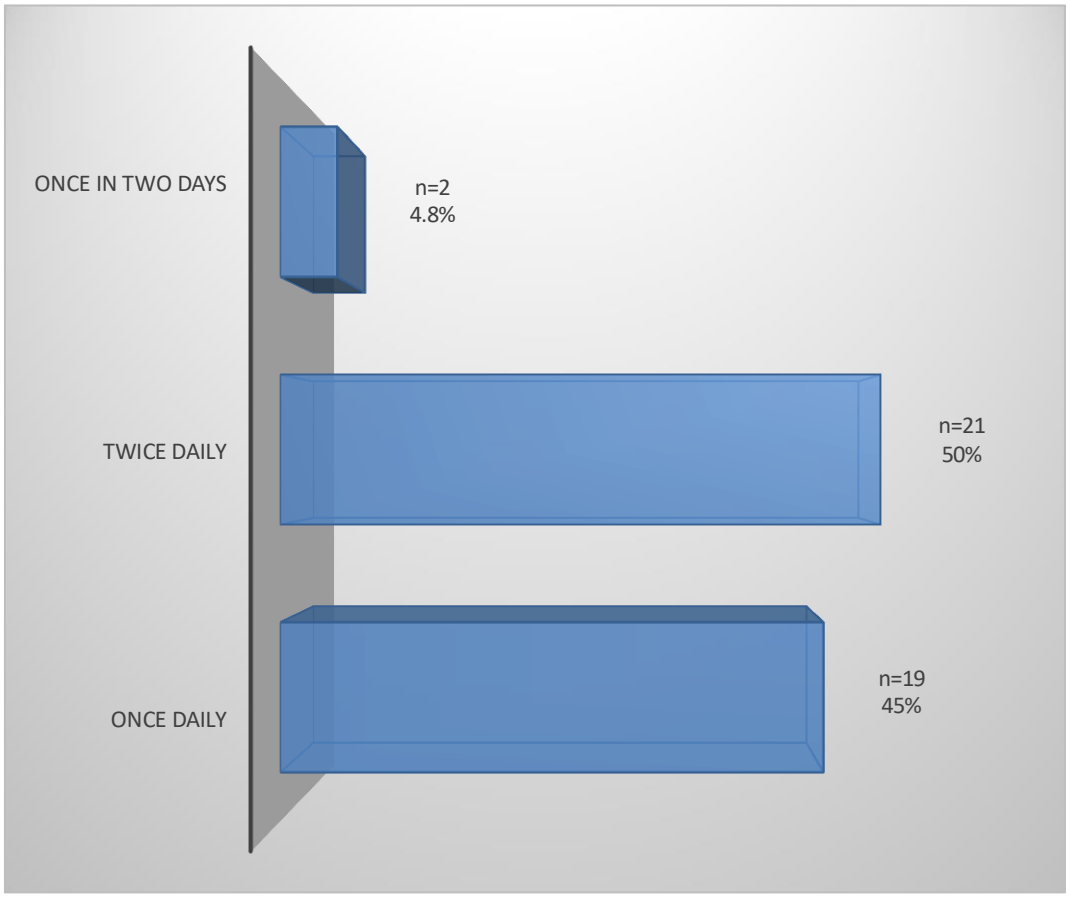

Figure 05: Take care of skin of patient

In this study the knowledge of the attendants about take care of the patient's skin ,maximum 45%(n=19)were once daily, 50%(n=21) were twice daily and 4.8%(n=2) were once in two days.

4.2.2. Dressing of the patient :

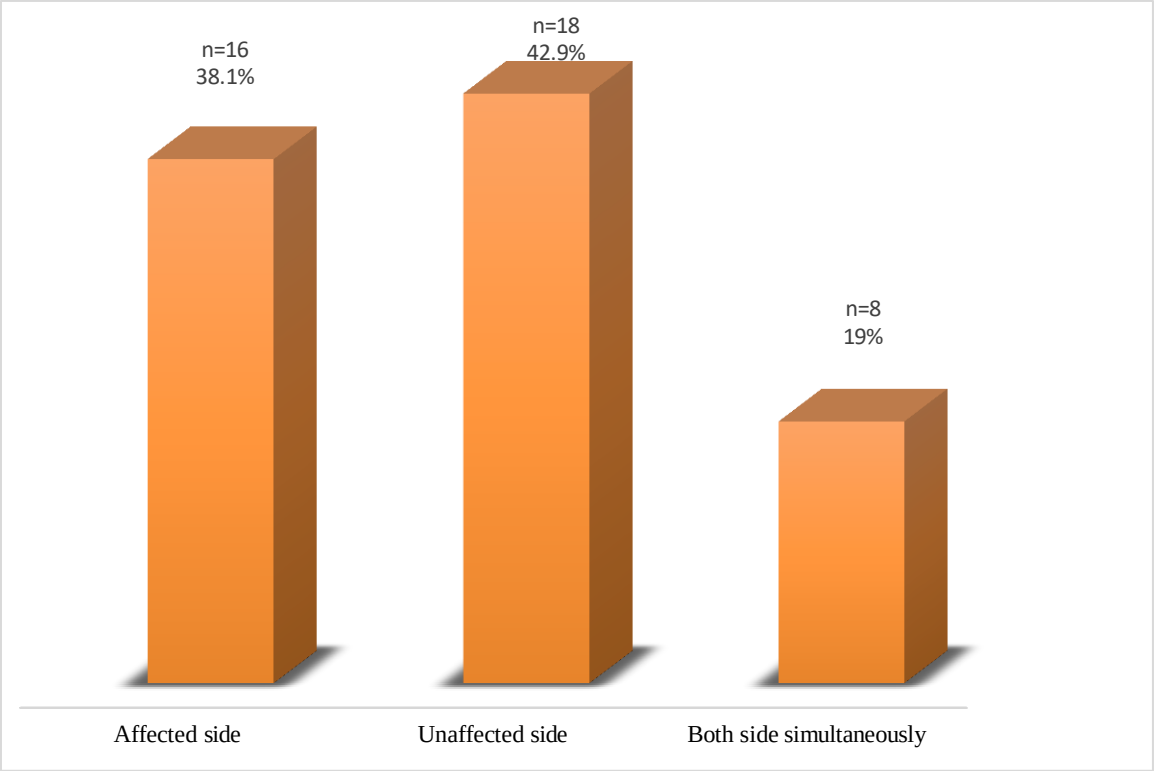

Figure 06: Dressing of the patient

In this study knowledge about putting the dress of the patient always start from unaffected size which is maximum 42.9%(n=18), 38.1%(n=16) were from affected side and 19%(n=8) were from both side simultaneously.

4.2.3. To prevent constipation :

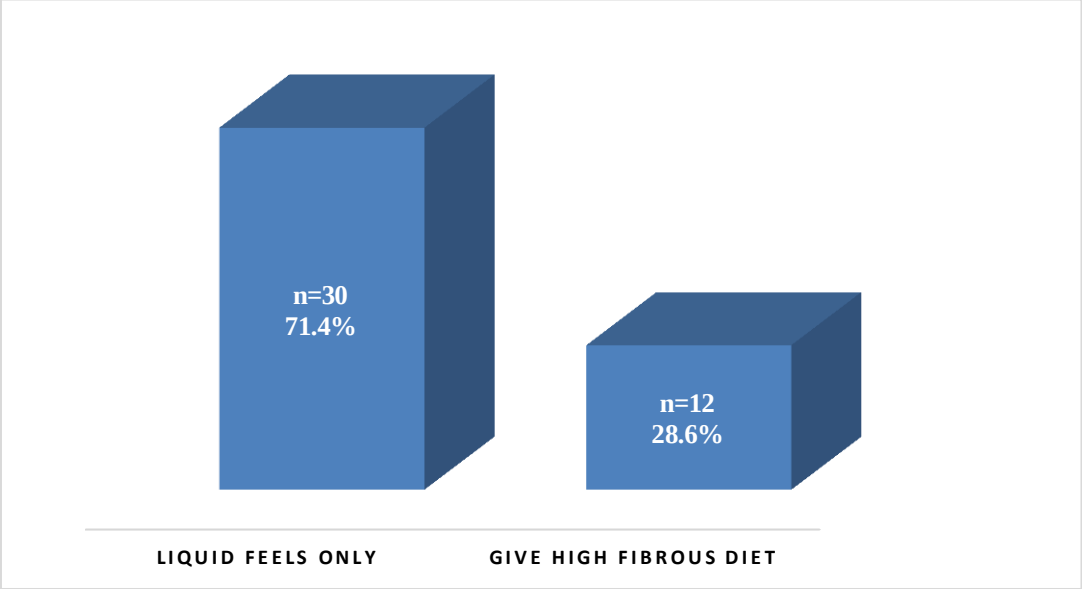

Figure 07: To prevent constipation

In this study the knowledge about the prevention of patient's constipation give the patient liquid feed were 71.4%(N=30) and high fibrous diet were 28.6%(n=12).

4.2.4. To prevent Urinary tract infection :

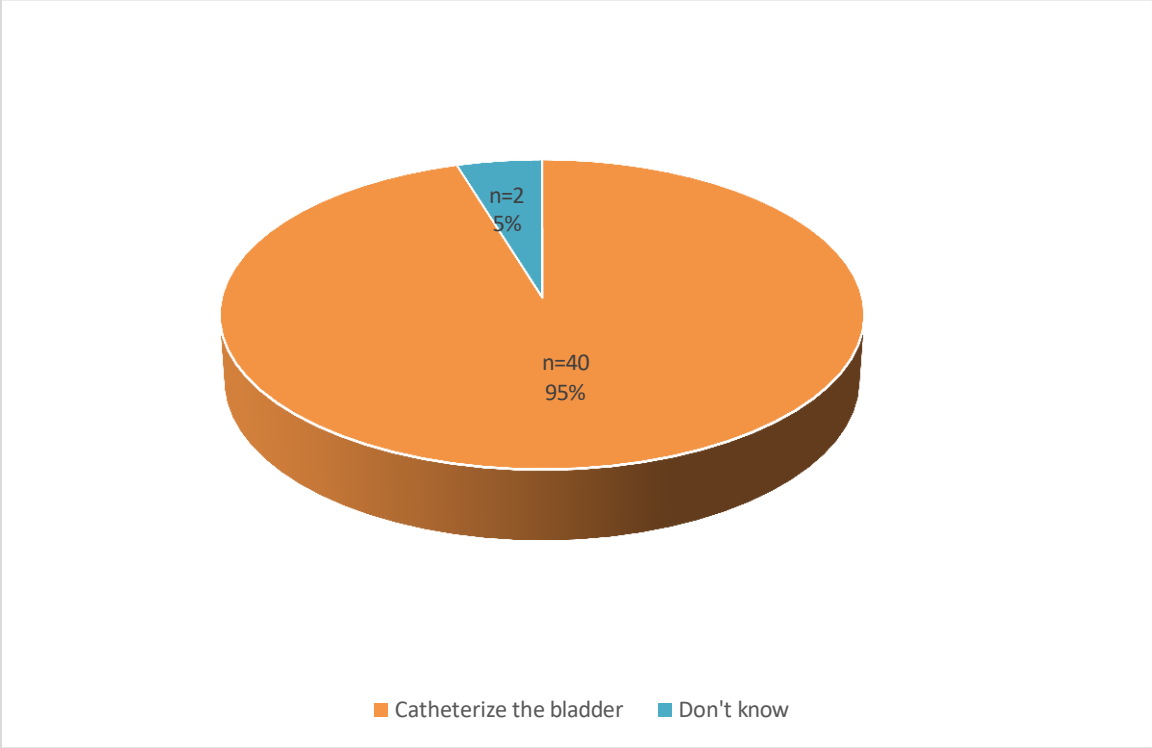

Figure 08: To prevent urinary tract infection

Among 42 participants knowledge about urinary tract infection prevention 95%(n=40) were catheterize the bladder and 5% were don't know about this.

4.2.5. To prevent contracture :

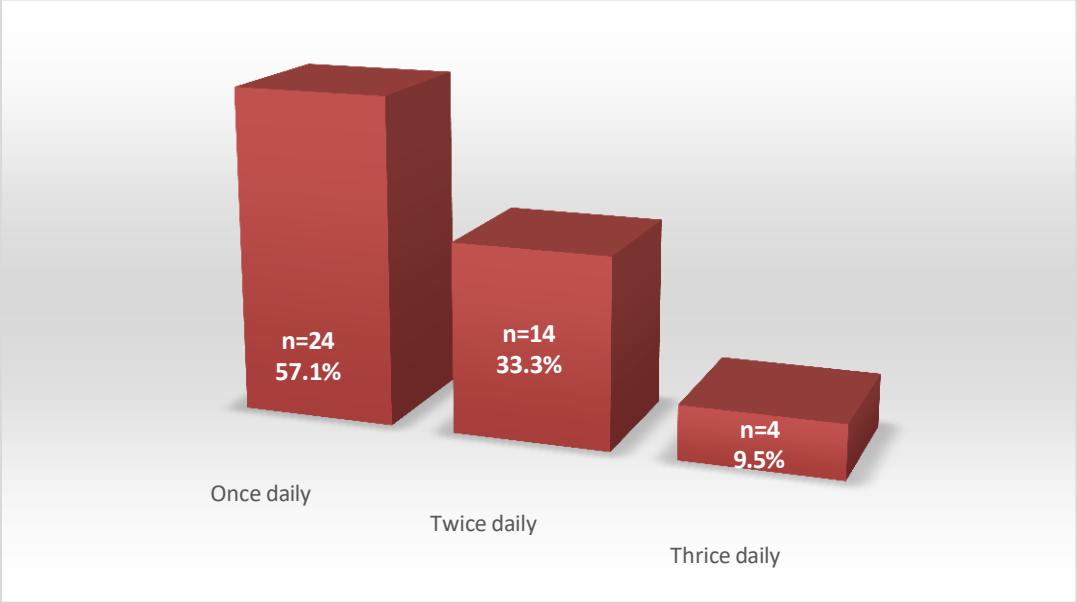

Figure 09: To prevent contracture

In this study the knowledge about prevention of contracture to perform active and passive exercise 57.1%(n=24) were once daily, 33.3%(n=14) were twice daily, 9.5%(n=4) were thrice daily.

4.2.6. To prevent pressure sore :

The knowledge about the prevention of pressure sore keep the patient in soft /cotton surface were maximum 100%(n=42).

Table 05: To prevent pressure sore

To prevent bed sore	Frequency (N)	Percent %
Soft/cotton surface	42	100.0%
Hard surface	0	0

4.2.7. To change the bed position :

In this study knowledge about changing tetraplegic patient's position were maximum 100%(n=42).

Table 06: To change the bed position

How often should change the bed position	Frequency (N)	Percent %
2 hourly	42	100.0
4 hourly or above	0	0

4.2.8. Prognosis of patient :

In this study the Knowledge or idea about patient's prognosis were maximum 100%(n=42).

Table 07: Prognosis of patient

Idea about prognosis of Patients	Frequency (N)	Percent %
Yes	42	100.0
No	0	0

4.3. Low back pain related questionnaire :

4.3.1. Suffering from LBP during take care of the patient :

In this study attendants were suffering from LBP were maximum 100% (n=42).

Table 08: Suffering from LBP during take care of the patient

Suffering from LBP	Frequency (N)	Percent %
Yes	42	100.0
No	0	0

4.3.2. Limitation of activities due to LBP

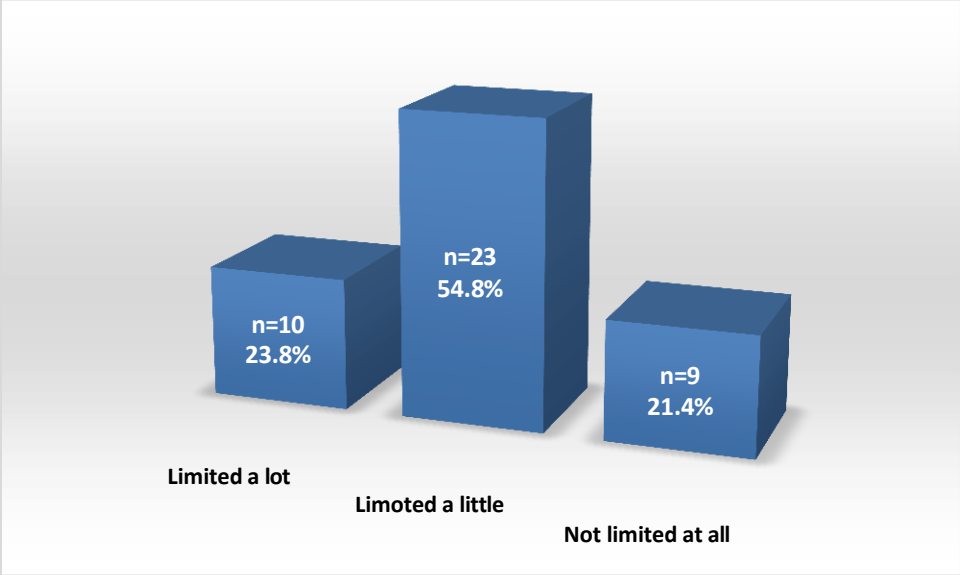

Figure 10: Limitation of activities due to LBP

In this study, limitation of activities of the attendants of the patients were maximum limited a little 54.8%(n=23), limited a lot 23.8%(n=10) and not limited at al 21.4%(n=9).

4.3.3. Pain in VAS scale :

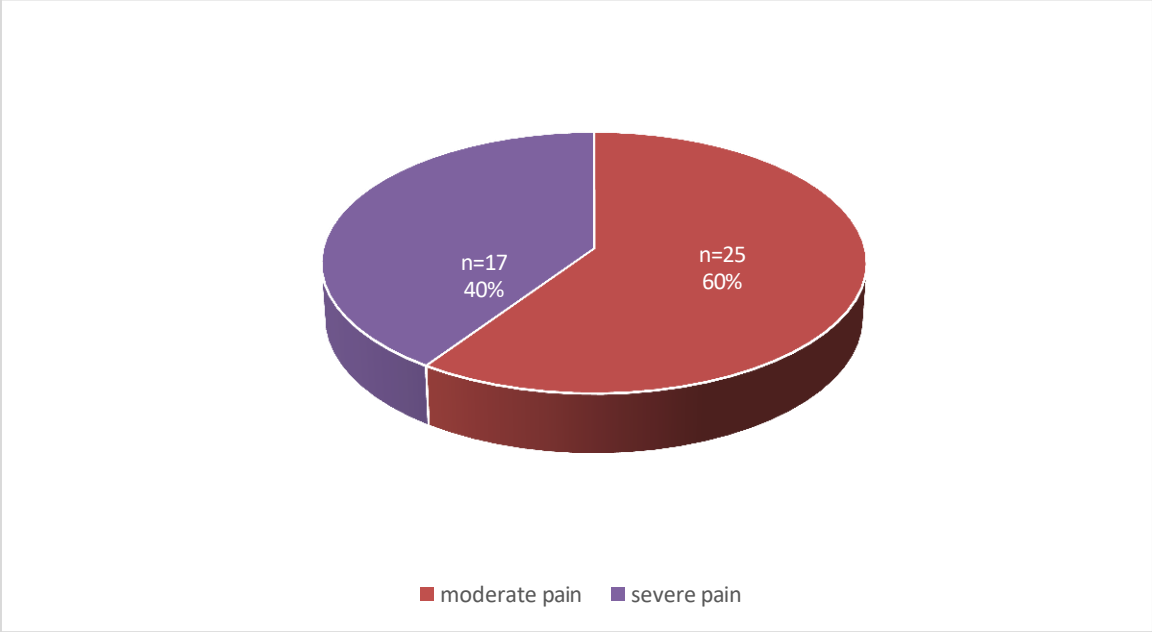

Figure 11 : Pain in VAS scale

In this study maximum pain of the attendants were severe low back pain 60%(n=25) and moderate low back pain were 40%(n=17) and there were no mild pain.

4.4. Generalized Anxiety Disorder (GAD) total score :

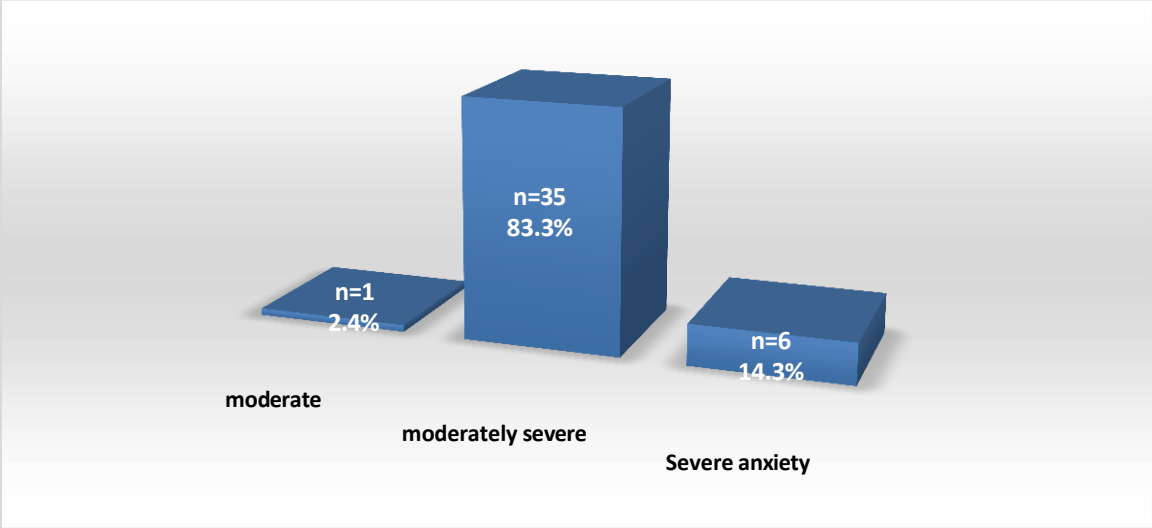

Figure 12: Generalized Anxiety Disorder (GAD) total score

The column chart showed that among 42 respondents, there were maximum 83.3% (n=35) of the respondents who had moderate anxiety, 14.3%% (n=6) of the respondents had severe anxiety, 2.4% (n=1) of the respondents had mild anxiety.

4.5. Patients Health Questionnaire (PHQ) total score :

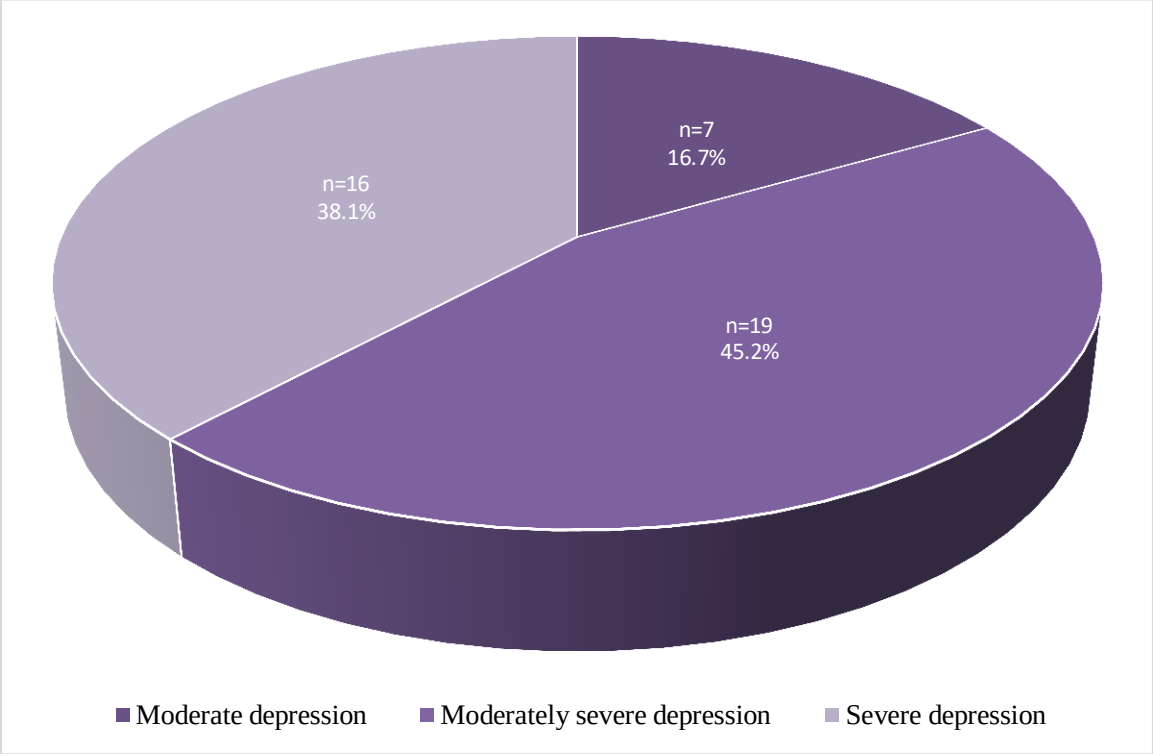

Figure 13: Patients Health Questionnaire (PHQ) total score

Among 42 participants it was found that 38.1%(n=16) of the participants had severe depression, 45.2%(n==19) participants had moderately severe depression, 16.7%(n=7) participants had moderate depression.

4.6. Zarit Burden Interview (ZBI) total score :

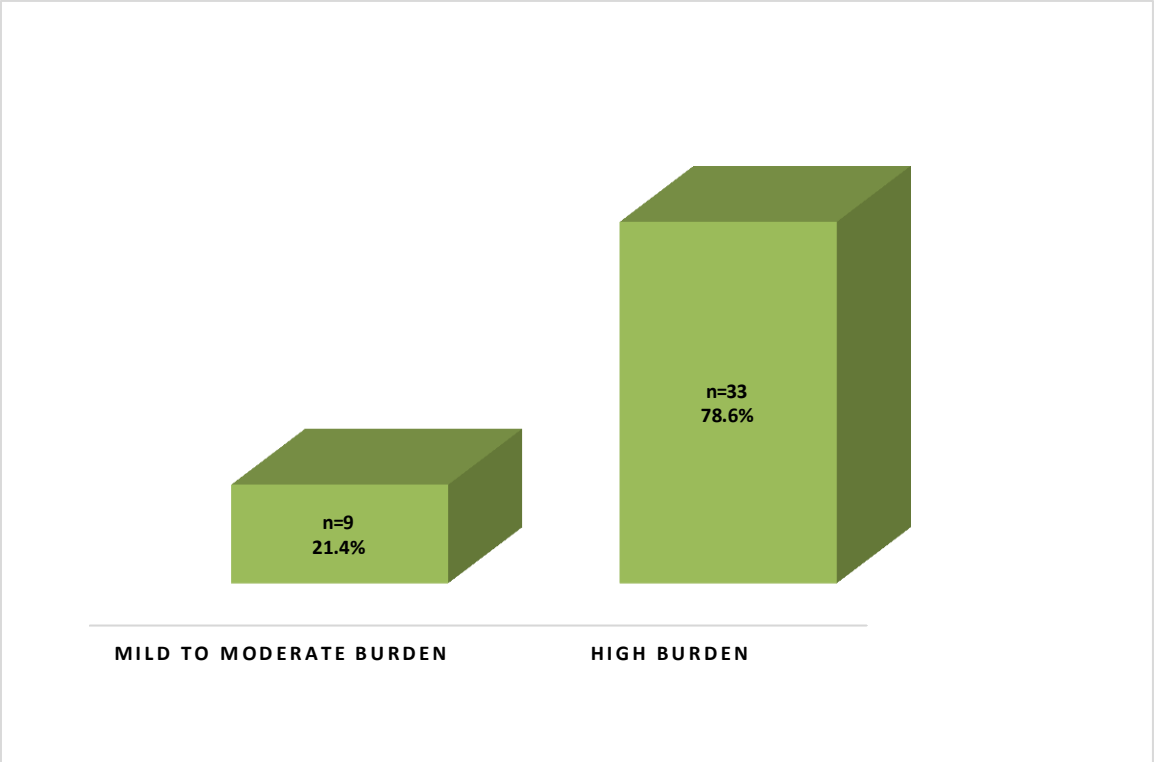

Figure 14: Zarit Burden Interview (ZBI) total score

Among 42 participants it was found that 78.6%(n=33) of the participants had high burden, 21.4%(n=9) participants had mild to moderate burden.

4.7. Analysis between subjects for association

In Chi-square test we see the association. If the P-value is <0.05 then the result is significant which means there is association between variables.

Table 4.7.1: Association of age and pain in VAS scale total score:

Age and pain in VAS scale total score	Chi-square	P-value
	12.946	.002

For association of age and pain in VAS scale total score p-value is .002 which is less than 0.05. So the result is significant and there is an association between age and pain in VAS scale score.

Table 4.7.2. Association of Age and Generalized Anxiety Disorder (GAD-7) total score:

Age and Generalized anxiety Disorder (GAD-7) total score	Chi-square	P-value
	1.010	0.908

For association of age and GAD-7 total score, P-value is 0.908 which is more than 0.05. So the result is not significant that indicates there is no association between age and GAD-7 total score.

Table 4.7.3: association of age and Patient Health Questionnaire (PHQ-9) total score:

Age and Patient Health Questionnaire (PHQ-9) total score	Chi-square	P-value
	5.386	0.250

For association of age and Patient Health Questionnaire (PHQ-9) total score, P-value is 0.250 which is more than 0.05. So the result is insignificant that indicates there is no association between age and Patient Health Questionnaire (PHQ-9) total score.

4.7.4 : Association of age and Zarit Burden Interview (ZBI) total score:

Age and Zarit Burden Interview (ZBI) total score	Chi-square	P-value
	6.121	0.013

For association of age and Zarit Burden Interview (ZBI) total score, P-value is 0.809 which is more than 0.05. So the result is insignificant that indicates there is no association between age Zarit Burden Interview (ZBI) total score.

4.7.5 : Association of gender and pain in VAS scale total score:

Gender and pain in VAS scale total score	Chi-square	P-value
	3.796	0.05

For association of gender and pain in VAS scale total score, P-value is 0.05. So the result is significant that indicates there is association between gender and pain in VAS scale total score.

4.7.6 : Association of gender and Generalized Anxiety Disorder (GAD-7) total score:

Gender and Generalized Anxiety Disorder (GAD-7) total score	Chi-square	P-value
	3.608	0.165

For association of gender and Generalized Anxiety Disorder (GAD-7) total score, P-value is 0.165 which is more than 0.05. So the result is insignificant that indicates there is no association between gender and Generalized Anxiety Disorder (GAD-7) total score.

4.7.7 : Association of gender and Patient Health Questionnaire (PHQ-9) total score:

Gender and Patient Health Questionnaire (PHQ-9) total score	Chi-square	P-value
	4.961	0.084

For association of gender and Patient Health Questionnaire (PHQ-9) total score, P-value is 0.084 which is more than 0.05. So the result is insignificant which points out that there is no association between gender and Patient Health Questionnaire (PHQ-9) total score.

4.7.8 : Association of gender and Zarit burden Interview (ZBI) total score:

Gender and Zarit burden Interview (ZBI) total score	Chi-square	P-value
	0.424	0.809

For association of gender and Zarit burden Interview (ZBI) total score, P-value is 0.013 which is less than 0.05. So the result is significant which points out that there is association between gender and Zarit burden Interview (ZBI) total score.

4.7.9 : Association of living area and Generalized Anxiety Disorder (GAD-7) total score:

Living area and Generalized Anxiety Disorder (GAD-7) total score	Chi-square	P-value
	1.976	0.372

For association of living area and Generalized Anxiety Disorder (GAD-7) total score, P-value is 0.372 which is more than 0.05. So the result is insignificant which points out that there is no association between living area and Generalized Anxiety Disorder (GAD-7) total score.

4.7.10 : association of living area and Patient Health questionnaire (PHQ-9) total score:

Living area and Patient Health questionnaire (PHQ-9) total score	Chi-square	P-value
	0.601	0.740

For association of living area and Patient Health questionnaire (PHQ-9) total score, P-value is 0.740 which is more than 0.05. So the result is insignificant which points out that there is no association between living area and Patient Health questionnaire (PHQ-9) total score.

4.7.11 : Association of living area and Zarit Burden Interview (ZBI) total score:

Living area and Zarit Burden Interview (ZBI) total score	Chi-square	P-value
	2.695	0.101

For association of living area and Zarit Burden Interview (ZBI) total score, P-value is 0.101 which is more than 0.05. So the result is insignificant which points out that there is no association between living area and Zarit Burden Interview (ZBI) total score.

4.7.12 : association of educational status and Generalized Anxiety Disorder (GAD-7) total score:

Educational status and Generalized Anxiety Disorder (GAD-7) total Score	Chi-square	P-value
	11.672	0.166

For association of educational status and Generalized Anxiety Disorder (GAD-7) total score, P-value is 0.166 which is more than 0.05. So the result is insignificant which indicates that there is no association between educational status and Generalized Anxiety Disorder (GAD-7) total score.

4.7.13 : Association of educational status and Patient Health questionnaire (PHQ-9) total score:

Educational status and Patient Health questionnaire (PHQ-9)	Chi-square	P-value
	7.613	0.472

total score		

For association of educational status and Patient Health questionnaire (PHQ-9) total score, P-value is 0.472 which is more than 0.05. So the result is insignificant which indicates that there is no association between educational status and Patient Health questionnaire (PHQ-9) total score.

4.7.14 : Association of educational status and Zarit Burden Interview (ZBI) total score:

Educational status and Zarit Burden Interview (ZBI) total score	Chi-square	P-value
	2.333	0.675

For association of educational status and Zarit Burden Interview (ZBI) total score, P-value is 0.675 which is more than 0.05. So the result is insignificant which indicates that there is no association between educational status and Zarit Burden Interview (ZBI) total score.

4.7.15 : Association of occupation and pain in VAS scale total score:

Occupation and pain in VAS scale total score	Chi-square	P-value
	8.308	0.081

For association of occupation and pain in VAS scale total score, P-value is 0.081 which is more than 0.05. So the result is insignificant which indicates that there is no association between occupation and pain in VAS scale total score.

4.7.16 : Association of occupation and Generalized Anxiety Disorder (GAD-7) total score:

Occupation and Generalized Anxiety Disorder (GAD-7) total	Chi-square	P-value
	13.821	0.087

Score		

For association of occupation and Generalized Anxiety Disorder (GAD-7) total score, P-value is 0.087 which is more than 0.05. So the result is insignificant which indicates that there is no association between occupation and Generalized Anxiety Disorder (GAD-7) total score.

4.7.17 : Association of occupation and Patient Health Questionnaire (PHQ-9) total score:

Occupation and Patient Health Questionnaire (PHQ-9) total score	Chi-square	P-value
	19.271	0.013

For association of occupation and Patient Health Questionnaire (PHQ-9) total score, P-value is 0.013 which is less than 0.05. So the result is significant which indicates that there is association between occupation and Patient Health Questionnaire (PHQ-9) total score.

4.7.18 : Association of occupation and Zarit Burden Interview (ZBI) total score:

Occupation and Zarit Burden Interview (ZBI) total score	Chi-square	P-value
	4.351	0.361

For association of occupation and Zarit Burden Interview (ZBI) total score, P-value is 0.361 which is more than 0.05. So the result is insignificant which indicates that there is no association between occupation and Zarit Burden Interview (ZBI) total score.

4.7.19 : Association of marital status and Generalized Anxiety Disorder (GAD-7) total score:

Marital status and Generalized Anxiety	Chi-square	P-value
	5.050	0.080

Disorder (GAD-7) total Score		

For association of marital status and Generalized Anxiety Disorder (GAD-7) total score, P-value is 0.080 which is more than 0.05. So the result is insignificant which indicates that there is no association between marital status and Generalized Anxiety Disorder (GAD-7) total score.

4.7.20 : Association of marital status and Patient Health Questionnaire (PHQ-9) total score:

Marital status and Patient Health Questionnaire (PHQ-9) total score	Chi-square	P-value
	0.032	0.984

For association of marital status and Patient Health Questionnaire (PHQ-9) total score, P-value is 0.984 which is more than 0.05. So the result is insignificant which indicates that there is no association between marital status and Patient Health Questionnaire (PHQ-9) total score.

4.7.21 : Association of marital status and Zarit Burden Interview (ZBI) total score:

Marital status and Zarit Burden Interview (ZBI) total score	Chi-square	P-value
	1.347	0.246

For association of marital status and Zarit Burden Interview (ZBI) total score, P-value is 0.246 which is more than 0.05. So the result is insignificant which indicates that there is no association between marital status and Zarit Burden Interview (ZBI) total score.

4.7.22 : Association of relationship with patient and Generalized Anxiety Disorder (GAD-7) total score:

Relationship with patient	Chi-square	P-value

and Generalized Anxiety Disorder (GAD-7) total score	11.623	0.476

For association of relationship with patient and Generalized Anxiety Disorder (GAD-7) total score, P-value is 0.476 which is more than 0.05. So the result is insignificant which indicates that there is no association between relationship with patient and Generalized Anxiety Disorder (GAD-7) total score.

4.7.22: Association of relationship with patient and Generalized Anxiety Disorder (GAD-7) total score:

Relationship with patient and Patient Health questionnaire (PHQ-9) total score	Chi-square	P-value
	15.467	0.217

For association of relationship with patient and Patient Health questionnaire (PHQ-9) total score, P-value is 0.217 which is more than 0.05. So the result is insignificant which indicates that there is no association between relationship with patient and Patient Health questionnaire (PHQ-9) total score.

4.7.24 : Association of relationship with patient and Zarit Burden Interview (ZBI) total score:

Relationship with patient and Zarit Burden Interview (ZBI) total score	Chi-square	P-value
	5.543	0.47

For association of relationship with patient and Zarit Burden Interview (ZBI) total score, P-value is 0.476 which is more than 0.05. So the result is insignificant which indicates that there is no association between relationship with patient and Zarit Burden Interview (ZBI) total score.

4.7.25 : Association of monthly income and Generalized Anxiety Disorder (GAD-7) total score:

Monthly income and Generalized Anxiety Disorder (GAD-7) total Score	Chi-square	P-value
	8.329	0.080

For association of monthly income and Generalized Anxiety Disorder (GAD-7) total score, P-value is 0.080 which is more than 0.05. So the result is insignificant which indicates that there is no association between monthly income and Generalized Anxiety Disorder (GAD-7) total score.

4.7.26 : Association of monthly income and Patient Health Questionnaire (PHQ-9) total score:

Monthly income and Patient Health Questionnaire (PHQ-9) total score	Chi-square	P-value
	4.379	0.357

For association of monthly income and Patient Health Questionnaire (PHQ-9) total score, P-value is 0.375 which is more than 0.05. So the result is insignificant which indicates that there is no association between monthly income and Patient Health Questionnaire (PHQ-9) total score.

4.7.27 : Association of monthly income and Zarit Burden Interview (ZBI) total score:

Monthly income and Zarit Burden Interview (ZBI) total score	Chi-square	P-value
	3.204	0.201

For association of monthly income and Zarit Burden Interview (ZBI) total score, P-value

is 0.201 which is more than 0.05. So the result is insignificant which points out that there is no association between monthly income and Zarit Burden Interview (ZBI) total score.

4.7.28. Association of Pain and Generalized Anxiety Disorder (GAD-7) total score:

Pain and Generalized Anxiety Disorder (GAD-7) total score	Chi-square	P-value
	0.909	0.63

For association of pain and Generalized Anxiety Disorder (GAD-7) total score, P-value is 0.63 which is more than 0.05. So the result is insignificant which points out that there is no association between pain and Generalized Anxiety Disorder (GAD-7) total score.

4.7.29. Association of pain and Patient Health Questionnaire (PHQ-9) total score:

Pain and Patient Health Questionnaire (PHQ-9) total score	Chi-square	P-value
	8.085	0.01

For association of pain and Patient Health Questionnaire (PHQ-9) total score, P-value is 0.01 which is less than 0.05. So the result is significant which points out that there is an association between pain and Patient Health Questionnaire (PHQ-9) total score.

4.7.30. Association of Generalized Anxiety Disorder (GAD-7) and Zarit Burden Interview (ZBI) total score:

Generalized Anxiety Disorder (GAD-7) and Zarit Burden Interview (ZBI) total score	Chi-square	P-value
	0.396	0.820

For association of Generalized Anxiety Disorder (GAD-7) and Zarit Burden Interview (ZBI) total score, P-value is 0.82 which is more than 0.05. So the result is insignificant which points out that there is no association between Generalized Anxiety Disorder (GAD-7) and Zarit Burden Interview (ZBI) total score.

4.7.31. Association of Patient Health Questionnaire (PHQ-9) and Zarit Burden Interview (ZBI) total score:

Patient Health Questionnaire (PHQ-9) and Zarit Burden Interview (ZBI) total score	Chi-square	P-value
	3.564	0.16

For association of Patient Health Questionnaire (PHQ-9) and Zarit Burden Interview (ZBI) total score, P-value is 0.16 which is more than 0.05. So the result is insignificant which points out that there is no association between Patient Health Questionnaire (PHQ-9) and Zarit Burden Interview (ZBI) total score.

CHAPTER V DISCUSSION

The purpose of the study to assess the knowledge, experience and burden among the attendants who have experienced to manage tetraplegic SCI patients.

Now a days spinal cord injury is a common accident which affects the patients quality of life badly. SCI greatly reduces the quality of life of the caregiver because they are fully depend on the attendants. There is comparatively little research in the literature on the knowledge, experience(quality of life) and burden of main carers of SCI survivors. This chapter represents the discussion of the results of the study in relation to the research questions and objectives of the study. The discussion is focused on assessing knowledge, identifying the level of depression, anxiety, pain and burden with their association for patients with tetraplegic spinal cord injury patients.

In this study self- made questionnaire is used for assessing the knowledge of the caregivers about the care of tetraplegic SCI patients.PHQ-9 (Patient health questionnaire-9) scale is used to measure the severity of depression. GAD-7 (Generalized Anxiety Disorder-7) scale is used to measure the level of anxiety and ZBI (Zarit Burden Interview) scale is used to assess the burden. Sociodemographic characteristics play a played an important role in association with knowledge, experience and burden of attendants in this study. There had an association between socio- demographic factors and knowledge, between socio-demographic factors and experience and between socio-demographic factors and burden.

In our study 42 persons are participate. There minimum age group is 15 years and maximum age group is 65 years. Mean age group is 1.43. Standard deviation is .547 .Most of the participants 58.1% %(n=25) were 15-35 age group. A study of Caregivers, Knowledge, Attitude and Practice Towards the Pressure Care of Tharu et al., (2022) found that the mean age of the persons was 41.3 and standard deviation was 12.1. Among 42 participants of our study, there are higher number of Attendants 93% (n=39) are female and 7% (n=3) of them are male. A study of Tharu et al., 2012 found that among 127 participants 76.4%(n=97) are female and 23.6% (n=30) are male. So it is

found that there are more permeability of female are higher than male. In our study participants most them 72.1%(n=31) are married . In a research, the majority of the participants were married 86.6% (Tharu et al., 2022).

In our study, educational level of the participants 16.3% (n=7) were uneducated, 27.9% (n=12) were primary, 43% (n=18) participants had secondary education, 7% (n=3) participants got higher secondary education, 4.7%(n=2) were graduated. A study showed that among 127 participants of their study 37%(n=47) were uneducated, 25.2%(n=32) were primary, 18.9%(n=24) were secondary, 13.4%(n=17) were higher secondary and 5.5%(n=7) were graduate and above (Tharu et al., 2022)

In our study among 42 participants occupation of them 17%(n=7) were businessman , 9.3%(n=4) were service holder, 4.7%(n=2) were day labour, 46.5%(n=20) were housewife , 20.9%(n=9) were student. Tharu et al., found that majority of housewife 69.3%, service holder 10.2%%, business 6.3%,student 6.3% and agriculture 1.6%.

Among 42 of our participant, 81% lived in rural area, 19% lived in urban area. In the study of tharu et al., 2022, 81.9% lived in rural area and 18.1% lived in urban area. In our study of 42 participants, relationship between attendants and patients 23.3%(n=10) were mother,5%(n=2) were daughter,14.0%(n=6) were father, 32.6%(n=13) were wife,7%(n=3) were husband, 16.3%(n=7) were son, 2.3(n=1) was brother. Tharu et.al., found that relationship between caregivers and patients 19.7% were mother, 5.5% were father, 40.9% were wife, 1.6% were husband,,6.3% were sister, 11.8% were brother and 14.2% were others.

Out of 42 participants, the maximum income is 22000 , minimum is 10000. In this study most of the participant’s income range from 10000-15000 group 39.5% (n=17), among 42of participant’s income 14% (n=6) in 15001-20000 group and 2.3% (n=1) in 20001-25000 group.

In my study which was consist of 42 participant, 100% (n=42) were suffering from LBP during taking care of patient. Among them limitation of activities little 54.8% (n=23), limited a lot 23.8% (n=10) and not limited at all 21.4% (n=9). Pain in VAS were severe 60% (n=25) and moderate were 40% (n=17).

Among 42 participants, I was found that 83.3% (n=35) of the participant had moderate anxiety which is maximum, 14.3% (n=6) had severe anxiety and 2.4% (n=1) had mild anxiety. According to Farajdadeh et al.,(2021) most of the participants (n = 58; 79.5%) were suffered from moderate to severe anxiety.

In our study of 42 participants, I was found that 38.1% (n=16) of the participant had severe depression, 45.2% (n=19) had moderately severe depression and 16.7% (n=7) had moderate depression. According to Rabi Zikic et al., (2019) found in their study was very similar to my study that among 73 of participants, minor depression was found in 86.7% and major depression in 13.3% of patients.

Among 42 participants, I was found that 78.6% (n=33) had high burden, 21.4% (n=9) had mild to moderate burden. According to Z.Khajaeipour et al.,(2017) the mean of caregivers' burden score was 38.9±15.2 and 11.7% reported no or little burden, 43.6% reported 'mild-to moderate' burden, 33.1% reported 'moderate-to-severe' burden and 11.7% reported 'severe' burden.

The Chi-square value between age and pain in VAS scale observed was 12.946 and P value was

0.02 (<0.05) that means the result was significant that indicate there have strong association of age and pain severity. But no association of anxiety, depression with age group.

The other studies showed the association of LBP with some demographic variables in case of female caregivers. Kelsey and Golden work in his research (2017) that age is associated with the occurrence of LBP and the likelihood of having LBP increases with age.

In my study, it was also indicated that there was an association between gender and LBP severity in VAS scale. Chi-square value was 3.796 and P-value 0.05 which was significant and there was a strong association between pain severity and depression. Chi square value 8.085 and P-value

0.01 which is significant. And there were no association between gender and anxiety P value

0.165 (p>0.05), between gender and depression p-value 0.08 (p>0.05) which was insignificant. Lynch and Kahalan, (2017) was found that there were no significant association of depression & gender and also there were no association of anxiety with the age and gender.

In my study there was a strong association between pain severity and depression. Chi square value 8.085 and P-value 0.01 which is significant.Association of occupation and depression there observed Chi-square value was 19.271 and P value was 0.013 (P<0.05) meaning that the result was significant that indicate there have association of occupation and depression. Farajzadeh et al.,(2021) found that there was no association between employment and mental health p-value

0.104 (P>0.05).

In my study it was indicate that there was no association between educational level depression, p-value-1.66 and between educational level and depression 0.472 which was insignificant. Farajzadeh et al., (2021) in their study found that there was no association between educational level and mental health (anxiety, depression) p-value 0.25 (p>0.05).

My study indicate that there was no association between relationship status and anxiety p-value

0.47 (P>0.05) and no association between relationship and depression p-value 0.21 (P>0.05). Farajzadeh et al., (2021) found that there was a strong association between relationship status and mental health P-value 0.018 (P<0.05).

In my study there was no association between marital status with anxiety P-value 0.080 and between marital status and depression P-value 0.98 which were insignificant. In the study of Farajzadeh et al., (2021) there was also no association of mental health and marital status P-value was 0.255 (P>0.05).

My study indicate that there was an association between age and burden score, p-value was

0.013 (P<0.05) which was significant. In the study of Z.Khajaeipour et al.,(2017) there was also an strong association with caregiver's age and burden P-value was 0.01 (P<0.05).

In my study association between participant's occupation and burden score was insignificant P- value 0.36 ($p>0.05$) and between relationship status and Burden score was P-value 0.47 ($P>0.05$) which was also insignificant and between educational level and burden score p-value 0.67 ($P>0.05$). Z.khajaeipour et al.,(2017) mentioned that there was a association between occupation and burden score which was P-value 0.041 and association between relationship status and burden score was P-value 0.025 ($P<0.05$).There was also an association between educational status and burden score P-value 0.03 ($P<0.05$).

5.1 Limitations of the study:

Regarding this study there were some situational limitation or barriers to consider the result of the study. The limitations are as below:

The study had small sample size. Only 42 samples were taken in this study. Only 42 samples do not represent the condition of entire country's attendant's knowledge, experiences and burden of tetraplegic SCI patients. It would be more effective if a large number of samples were taken. Time was one of the major limitation. I had a short period of time to complete the research so that large number of sample couldn't be managed for the study. The sample was collected only from CRP, Savar, Dhaka which might not represent the whole population within the context of Bangladesh. If it was collected from other many institutes and rehabilitation center across the country, the result would be more reliable and appropriate and also give a clear impression about the knowledge, experiences and burden of the attendants who are experienced to manage tetraplegic SCI patients. As it was the first research of the researcher so there might be some mistakes that should be overlooked by the supervisor and the honorable teachers.

CHAPTER V CONCLUSION AND RECOMMENDATION

6.1 Conclusion:

The study explores about knowledge, experiences and burden of tetraplegic SCI patient's attendants. The research highlights the considerable impact that tetraplegic SCI has on the family unit with many carers enduring a broad range of physical and mental health issues. Typically, carers assume their roles in early-middle age and may persist as primary carers for several decades. The results of the study suggest that low back pain, depression and anxiety are commonly experienced during caregiving a long period of time.This study has found the caregiver role to precipitate significant negative consequences including physical pain, depression, anxiety, burden.

These study results evidence that, among the 42 attendants of individuals with tetraplegic SCI, most of the attendants had a knowledge about properly managing of tetraplegic SCI patients. Most of them were female with low educational level. The QoL was worse for the domains role physical, bodily pain, mental, and role emotional. In the study it was found that there was strong association of age and pain severity experienced by them p-value was 0.002 ($P<0.05$) and there was an association between pain severity and depression p-value 0.01 ($P<0.05$). So caregivers age had a negative impact on their physical health during managing patient and also affect mental health. There was also an association found with age and burden p-value 0.013 ($P<0.05$). Occupation also found to be significantly associated with depression p-value 0.013 ($P<0.05$). So there may lack motivation to push himself/ herself during managing tetraplegic patient. But there was no significant association with age and anxiety, occupation and anxiety.

It has been also significant that there was an association between physical health and gender p- value 0.05. Female attendants are more suffer from LBP severity during managing the patients. Physical health and mental health may worse over time. It can make the pain worse, make sleep difficult, loose the energy, take away the enjoyment and make it difficult to take good care of health and that's why attendant felt a huge burden in their life. It not only affect the attendants life but also affect patients life as well as their prognosis.

6.2 Recommendation:

After completing the research, the researcher found some recommendation. Some points to be noted that might be taken for the better accomplishment for further study. The main recommendations would be as follow:

Should take more samples for generating the result and make more valid and reliable. Sample should collect from a whole country perspective with an increased sample size to generalize the result. To find out an effective and efficient result in generalized form, other measurement scales should be used in consideration. A larger sample size may increase the statistical significance of some of the result. There were some limitations of this study mentioned at the relevant section and it is recommended to overcome those limitations during further study.

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Appendix

Informed consent

(Please read out to the participant)

Assalamu Alaikum,

My name is Jannatul Ferdous Purba. I am conducting this research study which is the part of B.Sc. in Physiotherapy program and my research title is "Knowledge, Experience and Burden of the Attendant Who Have Experience to Manage Tetraplegic SCI Patients Attended at CRP" under Bangladesh Health Professions Institute (BHPI), University of Dhaka. Because of that I would like to know about some personal and other related information. This will take approximately 15-20 minutes.

I would like to inform you that this is a purely professional study and will not be used for any other purpose. All information provided by you will be treated as confidential and in the event of any report or publication it will be ensured that the source of information remains anonymous. Your participation in this study is voluntary and you may withdraw yourself at any time during this study without any negative consequences. You also have the right not to answer a particular question that you don't like or do not want to answer during interview.

If you have any query about the study or your right as a participant, you may contact with me or my supervisor Md Shofiqul Islam, Associate Professor and Head, Department of Physiotherapy, CRP, Savar, Dhaka-1343.

Do you have any questions before I start?

So, may I have your consent to proceed with the interview? Yes No

Signature of the Participant's..... Date… .....Signature of the Data collector's…… Date……

Date: 16th February 2023
The Chairman
Institutional Review Board (IRB)
Bangladesh Health Professions Institute (BHPI),CRP
Savar, Dhaka-1343.Bangladesh

Subject: Application for review and ethical approval.
Dear sir,

With due respect, I am Jannatul Ferdous Purba, student of B.Sc. in physiotherapy program at Bangladesh Health Professional Institute (BHPI) the academic institute of Centre for the Rehabilitation of the Paralyzed (CRP) under the Faculty of Medicine,University of Dhaka.As per the course curriculum, I have to conduct a dissertation entitled **"Assessment of Knowledge, Experiences and Burden of Caregivers Who Have Experience to Manage Tetraplegic SCI patients attendant at CRP"** under the supervision of Md Shofiqul Islam, Associate Professor, Department of Physiotherapy, BHPI.

The purpose of the study is to assess the knowledge, experiences and burden of the caregivers who have experience to manage tetraplegic SCI patients. The study involves face-to-face interview by using semi-structured questionnaire to explore the perception of the caregivers residing at Spinal Cord Injury Unit, CRP, Savar in Bangladesh that may take 30 to 40 minutes to fill in the questionnaire and there is no likelihood of any harm to the participants. Related information will be collected from the patients and medical record if necessary. Data collectors will receive informed consent from all participants andthe collected data will be kept confidential.

Therefore, I look forward to having your kind approval for the dissertation proposal and to start data collection. I can also assure you that I will maintain all the requirements for study.

Sincerely,

Jannatul Ferdous Purba

Jannatul Ferdous Purba
4th Year B.Sc. in Physiotherapy
Session: 2016-2017Student ID: 112160346
BHPI, CRP, Savar, Dhaka-1343, Bangladesh

Recommendation from the supervisor

Shofiq 16.02.23

Md Shofiqul Islam
Head of the Physiotherapy Department, BHPI.

Thesis presentation date: 9th January 2023

Shofiq 16.02.23

Head, Department of Physiotherapy, BHPI

Md. Shofiqul Islam
Associate Professor & Head
Department of Physiotherapy
Bangladesh Health Professions Institute (BHPI)
CRP, Chapain, Savar, Dhaka-1343

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

Ref: CRP/BHPI/IRB/3/2023/725 Date: 13/03/2023

To
Jannatul Ferdous Purba
B.Sc. in Physiotherapy,
Session: 2016-2017, DU Reg. No: 6875
BHPI, CRP, Savar, Dhaka- 1343, Bangladesh

Subject: Approval of the dissertation proposal **"Assessment of Knowledge, Experience and Burden of the Attendances Who Have Experience to Manage Tetraplegic SCI Patients Attendant at CRP"**- by ethics committee.

Dear
Jannatul Ferdous Purba,
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 Md Shofiqul Islam, Associate Professor, Head of the Department of Physiotherapy, BHPI, as dissertation supervisor. The following documents have been reviewed and approved:

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

The purpose of the study is to assess the knowledge, experience and burden of the attendances who have experience to manage tetraplegic SCI patients attendant at CRP. Should there any interpretation, type, spelling, grammatical mistakes in the title, it is the responsibilities of the investigator. Since the study involves questionnaire that takes maximum 20- 25 minutes and have no likelihood of any harm to the participants. The members of the Ethics committee approved the study to be conducted in the presented form at the meeting held at 09:00 AM on January 9, 2023 at BHPI, 34th IRB Meeting.

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

Best regards,

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

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

Date: March 28,2023

To

Head

Department of Physiotherapy

Centre for the Rehabilitation of the Paralysed (CRP)

Chapain, Savar, Dhaka-1343

Through: Head, Department of Physiotherapy, BHPI

Subject: Prayer for seeking permission to collect data for conducting a research project.

Sir,

With due respect and humble submission to state that I am Jannatul Ferdous Purba, student of 4th year B.Sc. in Physiotherapy at Bangladesh Health Professions Institute (BHPI). The Ethical committee has approved my research project entitled: **"Assessment of Knowledge, Experience and Burden of the Attendance Who Have Experience to Manage Tetraplegic SCI Patients Attendant at CRP"** under the supervision of Md. Shofiqul Islam, Associate Professor and Head, BHPI, CRP, Savar, Dhaka-1343. Conducting this research project is partial fulfillment of the requirement for the degree of B.Sc. in Physiotherapy. I want to collect data for my research project from Department of Physiotherapy. So, I need your kind permission for data collection at Spinal Cord Injury Unit of CRP, Savar, Dhaka. I would like to assure that nothing of the study would be harmful for the participants.

I therefore, pray and hope that your honor would be kind enough to grant my application and give me permission for data collection and oblige thereby.

Sincerely

Jannatul Ferdous Purba

Jannatul Ferdous Purba
4th Year
B.Sc. in Physiotherapy
Class Roll: 44; Session: 2016-17
Bangladesh Health Professions Institute (BHPI)
Chapain, CRP, Savar, Dhaka, 1343.

Recommended
Shofiq
28.03.2023

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Approved
28/03/23

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"A QUESTIONNAIRE TO ASSESS THE KNOWLEDGE, EXPERIENCE AND BURDEN OF ATTENDENT WHO HAVE EXPERIENCE TO MANAGE TETRAPLEGIC SCI PATIENTS ATTENDED AT CRP"

Part-1 **Sociodemographic Information**:

Patient's information	Attendance's information
Name:	Name:
Age:	Age:
Sex: Male Female	Sex: Male Female
Living Place: Urban Rural	Living Place: Urban Rural
Educational qualification: Never attended school Primary school Secondary school Higher secondary Bachelor or above Others (specify)	Educational qualification: Never attended school Primary school Secondary school Higher secondary Bachelor or above Others (specify)
Occupation: House wife Service Holder Business Student Others (specify)	Occupation: House wife Service Holder Business Student Others (specify)
Monthly income: Less than 10,000 10,000-30,000 30,000-50,000 More then 50,000	Monthly income: Less than 10,000 10,000-30,000 30,000-50,000 More then 50,000
Marital status: Married Unmarried Divorced Other	Marital status: Married Unmarried Divorced Other
Relationship with the attendance: Husband/Wife Father/Mother Brother/Sister Others (specify)	Relationship with the patient: Husband/Wife Father/Mother Brother/Sister Others (specify)

Part 2 -Knowledge :

How often should you take care of the skin of the patient
Once daily
Twice daily
Once in two days
Don't know
When dressing the client always start putting the dress from the-
Affected side
Unaffected side
Both side simultaneously
Don't know
To prevent constipation give-
Liquid feeds only
Give high fibrous diet
Give milk products
Don't know
How should you prevent urinary tract infection in your client?
Give more fluids
Use diapers
Catheterize the bladder
Don't know
To prevent contracture do active and passive exercise-
Once daily
Twice daily
Thrice daily
Don’t know
To prevent pressure sore you should keep the clint in
Hard surface

Cotton mattress
Water or air mattress
b. Don't know
How often should you change the position of your clint if bed ridden?
2 hours
4 hours
6 hours
Don't know
Do you have any idea about patient's prognosis?
Yes
No

Experiences :

Part-3 Anxiety measured by Generalized anxiety disorder 7 (GAD7)

Over the last two weeks how often have you been bothered by the following problems?	**Not at all**	**Several days**	**Over half the days**	**Nearlyevery days**
1.Feeling nervous, anxious	0	1	2	3
2.Not being able to control worrying	0	1	2	3
3.Worring too much about patient's condition	0	1	2	3
4.Trauble relaxing	0	1	2	3
5.Being so restless	0	1	2	3
6.Becoming easily annoyed or irritable	0	1	2	3
7. Feeling afraid as if something awful might happen	0	1	2	3

Part-4 Depression measured by the patient health questionnaire (PHQ) :

Over the last two weeks how often have you been bothered by any of the following problems?	**Not at all**	**Several days**	**More than half the days**	**Nearlyevery days**
1.Littleinterestin doing things	0	1	2	3
2.Feeling down, depressed or hopeless	0	1	2	3
3.Staying asleep	0	1	2	3
4.Feeling tired or having little energy	0	1	2	3
5.Feeling bad about yourself	0	1	2	3
6.Trauble concentrating on other household works	0	1	2	3
7.Found yourself getting agitated	0	1	2	3
8.Poor appetite/ overeating	0	1	2	3

9. Moving or speaking so slowly that other people could have noticed? Or the opposite-being so fidgety or restless that you have been moving around a lot more than usual	0	1	2	3

Part-5 Pain related questionnaire:

Do you experience back pain after starting caregiving?

Yes

No

Limitation of activities due to LBP :

Limited a lot

Limited a little

Not limited at all

On the scale of 0 to 10, with 0 being no pain at all and 10 being the worst pain imaginable, how would you rate your pain right now?

0 1 2 3 4 5 6 7 8 9 10

BURDEN:

Part-5 Burden measured by the Zarit Burden Interview Questionnaire (ZBI):

Questions	**NEVER**	**RARELY**	**SOMETIMES**	**QUITE FREQUENTLY**	**ALWAYS**
1.Do you feel that your relative ask for more help than he needs?	0	1	2	3	4
2.Do you feel that you don't have enough time for yourself?	0	1	2	3	4
3.Do you feel embarrassed about your patient condition?	0	1	2	3	4

4.Do you feel your health is suffered because your involvement on caregiving?	0	1	2	3	4
5.Do you feel stressed between caring your relative and trying to meet other responsibilities for your family or work?	0	1	2	3	4
6.Do you feel your relative depended on you?	0	1	2	3	4
7.Do you feel that you don't have much privacy because of your relatives?	0	1	2	3	4
8.Do you feel that social life has suffered because you are caring your relative?	0	1	2	3	4
9.Do you feel that you don't have enough money to take care of your patient in addition to the rest of your expenses?	0	1	2	3	4
10.Do you feel that you will be unable to take care of your patient much longer?	0	1	2	3	4
11.Do you wish you could leave the care to someone else?	0	1	2	3	4

12.Do you feel you could do a better job in caring for your patient?	0	1	2	3	4
13.Overall how burdened do you feel in caring for your relative?	0	1	2	3	4

Interpretation of score: 0-21: Mild burden
21-40: Moderate burden
>40: Severe burden

"টেট্রাপ্লেজিক েরাগীপ্লের জ ত্ত্বাবধায়েকর জ্ঞান, অজিজজ্ঞা এবং েবাঝার মূল্যায়ন করার জ নয একপ্লে প্রশ্নাবল্ ী"

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পা◌েট-(০২) জ্ঞান:

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৪) জামন না

০২) এখন টরাগীপ্লি ক· □□মা পড়াপ্লবা সবসময শুরু িরপ্লবা
১) প্রভামিত ম ি ফথদি
২) অপ্রভামিত ম ি ফথদি
৩) এিইসদঙ্গ উভয়ম ি ফথদি
৪) জামন না

০৩) টিাষ্টাটিনে প্রকিপ্লরাধ িরকপ্ল তিন
১) শুক□□ মা◌েু□ িরল খা ◌ে
২) উচ্চ আশাঁ যুক্ত খা ◌ে ম ন
৩) □কদর পণে ম ন
৪) জামন না

০৪) িকিাপ্লব আপনার টরাগীর মূত্রনাল্□ীর সংক্রমণ প্রকিপ্লরাধ িরা উকিক□?
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অজিজজ্ঞা :

পাপ্ল ে-(০৪): সাধারণ উপ্লেজগিজন বযাি ধ ৭ (জিএজি-৭) ট ারা পিরমাি জপ উপ্লেগ

জগ ট ই সপ্তাজ ধের আপিন জকবার িনম্নিল্তখ্জ সমসযা গুেল্ া ট ারা িবরক্ত জ েয়েছন?	এপ্লকমই না	েজব কিছু টিন	অধকে টিপ্ল্ ন র েবজি	প্রায় প্রজিপ্লিনই
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পাপ্ল ে-(০৫): েরাগীর স্বাজ য প্রশ্নাবল্ ী (িপএজহিকউ) ট ারা পিরমাি জপ িবষজনা:

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পাপ্ল ে-(০৬): জ ািজর বাজেেন ইন্টারজিউ প্রশ্নাবল্ ী (Pজ িবআই) ট ারা পিরমাপ করা েবাঝা :

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