IMPACTS OF SPINAL CORD INJURY ON PARTNERS: PERCEPTION OF THE WIVES

By

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Abstract

Background: Spinal cord injury is described as one of the most devastating neurological impairment. It has profound effects on both the spinal injured person and their spouses.

Objectives: The objectives are to identify the physical and psychosocial impact, identify the physical and psychosocial impact on the wives, and identify the impact on affecting relationship and intimacy.

Methodology: The study was a phenomenological qualitative research design to collect in-depth information of participants' perception. Purposive sampling was used and nine participants who met the inclusion criteria were selected. Semi-structured, face to face interviews were conducted to collect the data.

Result and Discussion: Most of the SCI patients has loss of movement and sensory, loss of bowel and bladder control. For these reason the wives of the persons with SCI have to handle their husband. They face different physical problems such as low back pain, hand pain, neck pain, shoulder pain and other problems due to handle their husbands. The wives of the person with SCI has worries, mental pressure about how to manage their family. They cannot perform their daily living activities according to previous routine. The research also indicates that most of the participants have intimate relationship with their husbands. They face difficulties with their father-in-laws house, because the people of father-in-law's house do not maintain communication and does not help economically. On the other hand they do not face any difficulties with their relatives.

Conclusion: Wives of the persons with SCI have negative impact on their physical, psychosocial component. They have also impacts on relationship with husband, family members and relative as well.

Key Words: *Spinal cord injury, Partner, Impacts of SCI on partner*

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Lists of Acronyms

SCI: Spinal Cord Injury
ADL: Activities of Daily Living
BHP: Bangladesh Health Professions Institute
CRP: Centre for the Rehabilitation of the Paralysed
QOL: Quality of Life
QCA: Qualitative content analysis
OTs: Occupational Therapist

CHAPTER 1
INTRODUCTION

Spinal cord injury (SCI) is a traumatic or non-traumatic, life altering event for the injured people. SCI puts tremendous stress on injured individuals and their families (Otaghsara *et al.*, 2014). It affects all aspects of the person's life. It leads to high level of long term disability, morbidity and mortality. SCI reduces mobility as well as vocational activities (Razzak, Hellal and Nuri, 2011). Persons with SCI have longer life difficulties than other conditions. As a result the patient has to depend on their caregiver (Otaghsara *et al.*, 2014). Caregivers for persons with SCI have to engage themselves for a long time in care-giving. There are various impacts on the caregivers of persons with SCI. Caregivers have to face, and to deal, with various problems such as physical, mental, social and economic etc. during providing care (Hess and Hough, 2012). These problems make burdens on caregivers and prevent them from providing better care.

The study of Iran, Ebrahimzadeh *et al.* (2013) stated that, the nursing of persons with SCI is usually done by family members, but most of the time it is the wives who are mainly worried about their partner. Partners not only play the role of wife but also work as a caregiver. The impact of SCI is not only on the survivors but also on the partner. In the acute phase after the injury, partners feel affected, and support is needed in relation to their own daily activities such as eating, resting, and managing suffering. Partners have to struggle for the injured partner to regain a well-functioning everyday life, and for reestablishing life as a couple. The partner struggles to manage the overwhelming amount of everyday tasks. Some partners want to reestablish their usual functions outside the family as well. Other partners focus on establishing a new life together. The partners experience much distress and appreciate any support they get, but feel that they are mainly left to manage the difficult course on their own (Angel and Buus, 2011). Different symptoms like physical and emotional stress, exhaustion, anger, depression are seen among the partners (Post, Bloeman and Witte, 2005). Those symptoms have negative impacts on the partners. The partners feel insecure and can suffer different levels of financial difficulties etc. The injured male partners want to be separated from their non-injured female partner. On the other hand sometimes the wives become stigmatized and discriminated against. The other family members, relatives and people in the local society do not treat the wives of injured persons normally.

In the Bangladeshi situation, it is seen that the wives are mostly engaged in caregiving for persons with SCI. The problem this brings means that their quality of life (QOL) is decreased. Therefore they cannot engage themselves properly in caregiving. It hampers both injured and non-injured partner. From the Bangladeshi perspective, it is important issue to conduct this study because it will be helpful to identify the impacts of SCI on the partners. This study is a on the about the impacts of SCI on wives from the wives' point of view.

1.1. Background

Many persons with SCI face challenges regarding their physical, psychological and social functioning. A significant proportion of persons with SCI need support in these areas for the rest of their lives. Dickson *et al.* (2010) has highlighted that, significant loss includes almost all domains of the injured person's life. These are loss of control, pleasure, sensation, independence, identity and impulsiveness. These often have a negative impact on the QOL of the persons with SCI and their partners. The persons with SCI consequently face difficulties in accepting themselves as a person with disability.

Dickson *et al.* (2010) also explored that, family caregivers operate as an important component of the health care delivery system. Being a partner of a person with SCI is not unproblematic. The partners as caregivers play a central role in facilitating the injured person's coping responses. According to Post, Bloeman and Witte (2005) it is also acknowledged that partners experience considerable distress, social isolation and family strain during caregiving. They also found that there were less psychological impacts of SCI on the partner. Freeman, (2011) found that wives also have to deal with some negative psychological consequences of SCI. These are depression and aggressive behavior by the persons with SCI.

A partner works as a key person for a person with SCI. An injured person needs assistance in performing activities of daily living (ADL's) like feeding, dressing, washing and bowel bladder management (Beauregard and Noreau, 2009). For these reasons caring for the patient is a full time job for the partner. Care receiving characteristics, for example: stress, coping strategies and social support, can also impact on the female partner (Ebrahimzadeh *et al.,* 2013). Persons with SCI suffer from anxiety and they think of themselves as a neglected person, so they do not want to receive care from their partner. Sometimes these problems create burdens for the partner. Partners of persons with SCI always think about the new horrible situation. They are always worried about the management of the family. The Researcher has stated some common impacts of SCI on the partners of persons with SCI. For this reason the researcher feels the necessity of conducting a study about the impacts of SCI on the partners of persons with SCI from the point of view of the wives.

Incidence of separation and divorce are increased following SCI. These problems occur because of difficult in adapting to new physical functions, faces difficulties to maintain relationship and/or unwillingness to live with a disabled person. Sometimes who are the partner they become fatigue, they neglect their own health needs and problems. The non-injured female partner may become slurred and dispossessed from the family as well as society because they are thought as responsible for their husband's illness (Angel and Buus, 2011).These problems hamper their healthy life, social life and family relationship also. This issue is very important in our socio-cultural aspect. To relieve the partner's experience of distress, and management of the difficult process on their own, requires more focus and support from the professionals. This support could make a positive difference to those couples.The partners also needs emotional support and concrete assistance to reduce those problems.

Researcher has completed basement placement in 2nd year in the SCI unit at Center for the Rehabilitation of the Paralysed (CRP). It is situated at Savar, Dhaka, Bangladesh. CRP is the renowned rehabilitation centre for the persons with SCI (Annual report of CRP, 2013-2014). Researcher observed that the wives of the patient have to faces difficulties as above mentioned. At that time researcher was curious to know about their physical, psychological, social life style. The partner also needs proper support during providing care to the injured persons. Therapists concentrate on this issue to improve QOL of the wives. There are no related and sufficient studies in Bangladesh. Completion of this study will find out the perception of the wives of persons SCI about specific impacts on the wives during providing care.

1.2. Significance

Caregivers take care of people with disabling diseases. Generally they are parents, wives, sibling, sons, daughters, close relatives, friends and neighbors (Family Caregiver Alliance, 2012). According to Hoque, Grangeon and Reed (2012) most of the SCI are male and the primary caregiver is wife in Bangladesh. They assist patients in managing medications, therapy and medical emergencies, provide supervision, emotional support, and assist in personal care, mobility and other ADL's. About 40% of persons with SCI need assistance in performing their important ADL's such as eating, dressing, personal hygiene, mobility etc. and provide their emotional support and physical care (Lindsey, 2003). Generally the persons with SCI depend on their caregivers and the married people depend on their wives. The caregivers as well as partners take part to handle the client. The researcher explained broadly about the impacts of SCI on the partner of person with SCI in daily life. This study also identified common challenges for a person with SCI which interfere the non-injured partner's activity. Persons with SCI experience changes in their different function. In addition to these physical changes, most persons also experience emotional distress. In case of those problems a partner provide more support to the person with SCI. On the other hand, the partners of the persons with SCI get insufficient support from the family members or relatives. Sometimes it makes the partner emotionally distressed. This is a more important issue in our society and culture. This study will be helpful to find out the perception of the wives about the impact of the SCI on partners of the persons with SCI.

Occupational therapists (OTs) work with both patient and caregiver (CAOT, 2013). If there are no intimacy among patients and their female partner it will hamper in providing intervention. By knowing the impacts of SCI on non-injured partner, an OTs can provide advice to the patient and partner. On the other hand the partners will be benefited by getting occupational therapy management.

Occupational therapy is a unique profession in Bangladesh (Wilson and Wilcok, 2005). Most of the people do not know about the profession and its services. The OTs and the students of occupational therapy will be able to enrich their knowledge and resource by using this study in Bangladesh. They will also establish different management strategies for the partners of the persons with SCI.

In rehabilitation program of SCI OTs and other professionals work together. By this study the other professionals will be benefited to have a proper guideline to think about the partners of the persons with SCI as a caregiver. They will set their management strategies for facilitating the treatment according to their profession.

1.3. Aim

The aim of the study is to explore the perception of the wives about the impacts of SCI in their life.

1.4. Objectives

- To identify the physical and psychosocial impact on the wives.
- To understand the impacts of SCI on wives in activities of daily living.
- To identify the impact on affecting relationship and intimacy

CHAPTER 2

LITERATURE REVIEW

Spinal cord is an important and vital part of human body. SCI can occur after a non-traumatic or traumatic injury in spinal cord. SCI has adverse effect on life; actually it is a life changing injury. It leads to a vast change in an individual's lifestyle. The person with SCI most of the times experience limitations in mobility and other body functions. Limitations in body functions and mobility affect their participation in ADL's (Chaves *et al.*, 2004). Moreover, as the individual has physical limitations, it leads him stressed about life. This stressing condition is created because of the difficulty in life adjustment. SCI mostly happens at youth and middle age which create great problems in the life of the affected individual's previous social and occupational life roles (Babamohammadi, 2011). All of these problems create tremendous challenges in not only adapting with physical aspects but also with the living situation, relationships and adjustments. SCI is occurred in spinal cord due to different causes.

2.1. Spinal cord

Spinal cord is cylindrical in shape and slightly flattened in anterior and posterior areas (Back, 2006). It begins at the foramen magnum in the skull and it continuous with the medulla oblongata in the brain. It terminates inferiorly at the level of the lower border of the first lumber vertebra. The location of the spinal cord is within the vertebral foramen which is called the vertebral canal (Snell, 2010). The vertebral bodies protect the spinal cord anteriorly and vertebral arches protect it laterally and posteriorly. Spinal cord is a communicating link between the spinal nerves and the brain. The spinal cord is the major canal through which motor and sensory information travels between the brain and the body (Kirshblum, 2011). The receptor of the body receives the sensory stimuli from environment which sends signal to the brain and then the brain sends its messages to the spinal nerves through spinal cord which causes movements of the body (Snell, 2010). Spinal cord becomes damage or gets injury then it is called SCI. SCI may responsible for interrupting whole body communication.

2.2. Spinal cord injury

SCI usually occurs after an unexpected, traumatic and non- traumatic damage to the spinal cord. This injury or damage results in fracture, dislocation of vertebrae, intervertebral discs which in turn rupture the spinal cord partially or completely. "*A Spinal cord Injury is defined as damage or trauma to the spinal cord that in turn results in a loss or impaired function resulting in reduced mobility or feeling*" (Quadriplegic and paraplegic spinal cord injury, 2005). SCI results from an accident that breaks or severely damages the spinal cord in the segments of neck and back.

People with a SCI need to adjust with their daily living activities post injury. They also have to adjust with their partner in their personal life. Kreuter (2002) mentioned that, many people with a SCI stated that intimate relationship was much more intimate and spiritual than it was prior to the injury. This study will discover the perceptions of the wives of the persons with SCI about the impacts of SCI on them.

2.3. Incidence and prevalence of SCI

In Bangladesh it is a common practice to carry heavy load on the head. Most of the SCI takes place due to accidental fall while carrying load (Hoque, Grangeon and Reed, 2012). In Bangladesh during harvesting season the farmers and laborers carry their products on their head and transport them from harvesting areas to local store houses or from one vehicle to another. The common causes of SCI in Bangladesh are fall while carrying heavy load on head, road traffic accidents, falling from a height, fall of a heavy object onto the head or neck, bull attack and diving into shallow water (Hoque, Grangeon and Reed, 2012; Razzak, Helal and Nuri, 2011). According to the WHO, between 20-40 people per million of population acquire spinal injury each year (Hasan *et al.*, 2009). According to the report of National SCI statistical center (NSCISC) among the developed countries only in the U.S.A. approximately 12000 new cases of SCI are found every year. Approximately 60% of cases occurred in people 16-40 years of age (Ottomaneli and Lind, 2009). Currently there is no accurate number of persons SCI in Bangladesh. Therefore it is difficult to know or estimate the total number of patients with SCI in Bangladesh. The most common age group for SCI ranges from 25-29 years in Bangladesh and 83% of them are male (Islam, Hafez and Akter, 2011). The appropriate marriage age in Bangladesh for male is 21 and for female is 18 (UNICEF, 2008). It is seen that most of the people get marriage in the ages of 25-29. The number of married person with SCI is about 54.70% in Bangladesh (Zabber, 2014). The persons who get SCI in this age, they mainly depend on their partner. Their partner play role not only as a wife but also caregiver. For this reason, physical, social, financial, mental etc. impacts of SCI are seen among the partner.

2.4. Complications of SCI

The major complication of SCI is paralysis in body part such as upper and lower extremities. A variety of complications can also result from SCI. The person with SCI might have the complications like lack of skin sensation, pressure sore, bowel and bladder complexities, respiratory complications, and autonomic dysreflexia, sexuality dysfunction etc. (Somers, 2006). According to the Adler (2006), there are some other complications like deep vein thrombosis, decreased vital capacity, osteoporosis, postural hypotension, spasticity and heterotopic ossification. From the practical observation of the researcher at CRP, it has been seen that the most common complication is pressure sore, urinary tract infection, bowel and bladder problem, burning sensation, autonomic dysreflexia, abdominal distension, psychosocial distress etc. One of the common complications of tetraplegic patient is respiratory distress or chest complication. These can be developed at any time after the injury. Complications can also develop during the rehabilitation phase and after discharge. Patient and caregiver education plays a great role for preventing these complications. In CRP it is seen that, the most of the male patients are taken care by their wives. SCI person gets strength if his wife be always by his side. Care of the partner besides treatment can minimize these complications because treatment becomes more effective if there is proper care (Niroshanie and Pinto, 2014).

2.5. Partner

According to Oxford Dictionary (2013) the definition of the partner is "*A husband or wife, considered in relation to their partner." or "either member of a married pair in relation to the other; one's husband or wife"* or *"a spouse; a husband" or "a wife or the person with whom one cohabits in a romantic relationship".* The partner is the key supports for persons with SCI. An intimate relationship is a primary source of physical and emotional support (Post, Bloeman and Witte, 2005). Partners are always anxious about their injured spouse. Partners always try to engage themselves in caregiving for improving their injured partners' life. They also play role as an important part during the rehabilitation phase of the injured partner.

2.6. Role of partner as caregiver

Rehabilitation is essential for the persons with SCI. Partners take care of the patient and maintain all things in rehabilitation of SCI. Partner provides care for longer periods of time, so the caregiving of partner is unique from other kinds of caregiving. Additionally, a married injured person expects first care from his partner (Bender, 2011). An injured person wants better care and empathy from their partner. They also depend on their partner for managing the new situation.

Moreover, the partner of the person with SCI must often play important roles of lover and caregiver. Partners who provide care want to be loved as a partner and not as a care provider. Caregiving sometimes change the balance in a relationship, possibly placing the relationship at risk (Kreuter, 2000). Caregiving has a negative influence on a couple's relationship of persons with SCI. Partners who are in a caregiving role they have the experiences of more stress, fatigue, and depression than their husbands and other spouses who are not caregivers.

In Bangladesh the wives of persons with SCI try heart and soul for their husband's betterment. Though there are different types of impacts of SCI on wives such as physical, mental, financial etc., but they always try to stay beside their injured husband. Wives are always conscious about their loving husband's conditions. They take care of their partner; provide emotional and physical support during the critical situation of SCI. This study will be helpful to explore the experience of wives about the impacts of SCI on them either negative or positive.

2.7. Partner support for the adjustment of persons with SCI

Support of a partner to the person with SCI is very essential for recovery. Physical and emotional support is provided by a partner in a critical part of rehabilitation for an individual with a SCI. Moreover, partner's supports are required for a successful reintegration into the community (Beauregard and Noreau, 2009). Stable relationships can impact positively on QOL in SCI (Smyth, 2013). Satisfactory level about relationship among partner in Bangladesh is about 17% minimum and 51% is maximum. Successful participation of person with SCI depends on the responsibilities of partner.

Smyth (2013) explored the experiences of wives of persons with SCI that they have feelings of shock, fear and uncertainty. Besides, they do not know about their husbands' survive. Feelings of frustration, helplessness and the sense of having a full-time burden are also noticed among the wives. Furthermore they express concerns about financial problems as well as possible health problems such as back pain, tiredness, neck pain, shoulder pain etc. Though there are various problems in their personal life but they feel that the injury brought them closer together as a couple. In a study it is also reported that their emotional relationship with their partner had become stronger as a result of the injury (Dickson *et al.,* 2010). Partner's support is important and integral part for the adjustment of SCI in such type of unexpected situation. Beside this, SCI have some other negative or positive impacts on the partners that affect the life of them.

2.8. Impacts of SCI on partner

While one member of a family sustains a SCI then other family members become concerned about the treatment and prognosis. The impacts of caregiving most frequently falls on the non-injured partner. Partners who provide care are often severely stressed, particularly due to health issues that arise after SCI. Partners of persons with SCI suffer emotional stress more than those of the injured partner. The non-injured partners are more depressed than their partners with disabilities. Partners have a higher incidence of physical stress, emotional stress, burnout, fatigue and anger than the partners or spouses who are not the caregivers. These may create mental stress for them. They also have to think about money requirement for intervention, management transportation and changes in their home environment (Beauregard and Noreau, 2009). The members who are caring for a person with SCI have to sacrifice their job or works, change scheduled activities, which have to be isolate from their usual activities of daily living (Ebrahimzadeh *et al.*, 2013).The impacts of SCI is more severe on pre-marriages than the post injury marriage. Another study suggested that people in pre-injury marriages receive more daily personal care assistance from their spouses than those in post-injury marriages (Garret, 2012). The partners of persons with SCI cannot attend and participate in any social function. They become isolated from their family, relatives, community. They cannot meet their own health needs, financial needs and recreational needs.

SCI positively or negatively affect the life of a partner's role as a care-giver from injury to reintegration. When persons with SCI require assistance in ADL's such as feeding, dressing, and bowel and bladder care, partners are often the primary source of assistance, even when attendant care is available. It is likely to bring about some distress and potentially a lower (QOL) (Beauregard and Noreau, 2009). Weitzenkamp *et al.* (2007) also found that, people with SCI become aggressive towards caregivers as well as partner, when they think that their needs are not being met as normal people. They become frustrated as a result of impairing or losing their capability to perform their ADL's. Another research found that the QOL of partners who are the primary caregivers of a SCI victim is significantly affected.However; it does not seem to have an additional impact on the primary caregiver's life quality (Unalan *et al.*, 2001). SCI causes of decreasing QOL, participation in activities of both person with SCI and their partner.

2.9. Impact of injury on changing relationships

Kreuter (2000) explored, it is possible that the greatest change of a marriage or relationship is presented by a traumatic and non-traumatic SCI. It found that patients and their partners experience various negative psychological reactions to the onset of disability and chronic illness. Injury can cause economic and emotional strain on a couple. Spouses of men with SCI reported that, changes in roles and altered expectations of their life with their partner. Some women felt that their role is no longer as a spouse but more of a caregiver to their husband. Others have a difficult time living with a spouse who is substantially different following an injury. As a whole, these women reported that the relationship changed (Beauregard and Noreau, 2009; Dickson *et al.*, 2010). Spouses, who provide care, are experienced loss and a vast change in relationship following SCI. In case of pre-injury marriage, women's lives may become detached from their partner's lives and they experienced loneliness because of their partner's disability (Dickson *et al.*, 2010).

SCI couples, who have post injury marriage, expressed less dissatisfaction with relationship and low levels of communication. On the other hand the couples who have pre-injury marriage expressed more dissatisfaction. There are different patterns of marriage and satisfaction for people with and without a physical disability. They found that among those with physical disabilities, men were more likely than women to be single. Relationship status is also related to well-being, because an intimate relationship can make the couple happy and pleased. Partner's physical and mental health, social relationships predicted injured person's outcomes. Adopting the role of the caregiver can badly affect the couple's relationship as the role of the partner (Dickson *et al.*, 2010). One of the problems associated with the role reverse from partner to caregiver includes the difficulty of returning to pre-injury levels of intimacy (Beauregard and Noreau, 2010; Dickson *et al.*, 2010).

Kreuter, (2000) found that, the experiences of sexual functioning, desire and activity, sexual behavior, satisfaction with sex life and aspects of the emotional quality of the relationship are lower among persons with a SCI. However, the emotional quality of the relationship did not differ for couples where one had a SCI. Beauregard and Noreaus's (2009) study suggests that, the quality of the emotional component of martial life does not appear to be affected by SCI, although the partners of those with a SCI did report significant issues regarding physical expressions of intimacy. Different problems like divorce, separation are seen in an intimate relationship that affects both patient's and partner's life.

Divorce statistics after a partner has a SCI vary according to different studies. Studies show a higher rate of divorce occurs amongst couples where one partner has a SCI than in the general population (Beauregard and Noreau, 2009). In another research of Dickson *et al.* (2010) divorce rates for couples married at the time of injury are estimated to be 1.5 to 2.5 times higher than that of the general population. However, for those relationships that survive the first few years, the divorce rates and overall life satisfaction are similar to that of the general population. Intimacy between the couples, however, can remain problematic.

An intimate relationship is very important for patient's outcome. Who has a good relationship with partner, that patient feel secured and supported. Patient also gets strength in mind, physically and emotionally. So partner plays an important role in management of a patient with SCI.

2.10. Role of occupational therapy for the partner

A caregiver is defined as an individual who cares for and assists a disabled, ill, or frail family member, spouse, or friend (Moghimi, 2007). Partners of persons with SCI work as a caregiver during providing care to their husband.

Caregivers are playing an increasingly important role in rehabilitation, even rehabilitation in the patient's home. Though the caregivers have roles for a period of time, but they are at risk to experience caregiver burden (Moghimi, 2007). This burden, which is the result of prolonged provision of physical, mental, and emotional support to the patient, can negatively affect the health of both the patient and the caregiver. OTs can provide assistance to those people who are ill. However, they also assist those people who are assuming the role of caregiver to a spouse who is ill. When the health of an individual declines, an OTs's role is to assist both the individual who is ill and the caregiver (Veterans Memorial Hospital, 2014). OTs educates the caregiver as well as the spouse about taking care of their own, coping strategies, managing their own health problems, managing the situation etc. OTs also motivates the spouse to continue treatment of the injured people, train about the patient handling technique and joint protection techniques.

In addition with an OTs assists is by providing suggestions on how to care for the individual who is person with SCI. OTs can also provide recommendations on how to modify the home environment in order to assist with safety or keep the individual as independent as possible. The OTs may recommend a toilet riser, railings on staircases, or adaptive equipment so the individual can remain safe in his/her own home while maintaining independence with daily activities such as dressing, toileting, or self-feeding. OTs mainly provides that information to the partner of the SCI person because the partner handles all of things in Bangladeshi situation.

As healthcare practitioners an OTs should be very concerned about the presence of caregiver burden and stress, because it has the potential to hamper the rehabilitation of the patients.

CHAPTER 3
METHODOLOGY

3.1. Study design

Qualitative method was chosen to conducting this study. The phenomenological qualitative study design was selected because this method helps to explore the in depth information on the perception of the participants (Hissong *et al.,* 2014). "*Qualitative research is a systematic method of inquiry and it follows the scientific method of problem solving to a considerable degree; however, it deviates in certain dimension"* (Thomas and Nelson, 2001). For this reason researcher was selected qualitative research design to identify participant's views, perceptions and experiences.

The aim of this study was to explore the perception of the wives about the impacts of SCI in their life. Qualitative study was suitable to explore the experience and perception. Qualitative approach was used to describe experiences of the participant (Magenuka, 2006). For this reason qualitative method was chosen. A qualitative design and semi-structured face to face interviews was conducted to identify the impacts of SCI on partner. As mentioned by Ohman (2005) that, there have been increasing number of qualitative methods in rehabilitation research because qualitative approaches help to derive new concept, theory and alternative of traditional treatment model. Moreover, it explores about human's practical life phenomenon. In this study researcher found this approach appropriate because each of the participants have an own point of view on their experience as a care provider. The participants were able to express a detailed view and their own thoughts, attitudes and perception regarding the impact of SCI. Researcher wanted to show the participant's experience not the researcher's view and on this regard. Qualitative research tells about ordinary people's understanding and explanation of their own reality, not the researcher's preconceived views and perceptions of others' reality (Ohman, 2005). This approach of qualitative method helped to show the participants actual response of their practical experience which lastly formed the theme of the study by the interpretation and judgment of the collected data.

3.2. Sampling

The researcher was interested to obtain perception of the participants. The study was a qualitative type of study. The researcher was interested to obtain a complete understanding of the incident by analyzing a range of participant’s experiences. Subjects were collected by using purposive sampling from the population who met the all inclusion criterions. Purposive sampling was used because the researcher could not find out whoever was available, but could use judgment to select a sample (Frankel and Wallen, 2000). This method was also used to find out lived experience of a specific population. In qualitative studies, the sample size was generally very small (Hissong *et al.*, 2014). Samples were selected from wives of tetraplegia persons. Participants were selected by using purposive sampling to conduct the study.

Aim of the study was to identify the wives’ perception of the patient with SCI about the impact on the wives. As there were many wives of the persons with SCI, the researcher selected the study participant by purposive sampling method. It is the most common type of non-probability sampling to complete the study within the fixed time period. Purposive sampling method is based on the knowledge of a population and the purpose of the study. The subjects are selected because of some characteristic (Crossman, n. d). Researcher took approximately about 9 wives of tetraplegia patient with SCI by data saturation. Saturation is the point in data collection when no new or relevant information emerges with respect to the newly constructed theory. When the theory appears to be strong, with no gaps or unexplained phenomena, saturation has been achieved and the resulting theory is more easily constructed. If the researcher does not attain data saturation, any resulting theory may be unbalanced, incomplete (SAGE research methods, 2013). In this study researcher used data saturation to achieve appropriate results.

3.3. Inclusion criteria

- Data were collected from the wives of tetraplegia SCI patient. Most of the tetraplegia patient is male and need more support than paraplegic patient. The impact is more seen on the female partner of the tetraplegia patients (Garrett, 2011).
- Participants were selected from 18years to 50 years. In Bangladesh the appropriate marriage age for girl is 18 (UNICEF Bangladesh, 2011) and after 50 years

different physical problem or degenerative changes may be seen among female (Women issues, n.d).

- Wives who are regular in care giving were selected. If they are not regular it is difficult to find out the particular impact (Post, Bloeman and Witte, 2005).
- Participants had intact speech and cognition because they have to explore their experiences.

3.4. Study setting

The researcher collected data from the inpatient unit of CRP, Savar, Dhaka. SCI patients are treated here. Most of the patients are male and they are taken care of by their wives because it is very difficult for the tetraplegia person to maintain their activities by their own. For this reason the married person is seen to take care of by their wives in admission period at hospital. It was easy for the researcher to gather information from the wives of the patients with SCI.

3.5. Informed consent

The researcher used an information sheet and consent form both in English and Bengali to take the participant's consent {APPENDIX-3 (English)} and {APPENDIX-4 (Bengali)}. Researcher informed the participant about details of the study by the information sheet which included the aim, objectives, way of collecting data from the participant and the ethical considerations of the study. There was included also a witness on the every session of data collection with each of the participant. The participant or the witness was asked to read the information sheet, but in case of the participant/witness, who is not literate, researcher will read that out to them. There also used the consent form containing the consent of the participant that she is participating in the study.

3.6. Field test

The researcher accomplished the field test with two participants before starting the collection of data. Researcher informed the participant about the aim and objectives of the study during interview session. Carrying out field test is a preparation of starting final data collection. It helped to make a plan that how the data collection procedure can be carried out, sorting out the difficulties during questioning, making a basic plan of questioning and if there is needed any modification of the questionnaire. The collected data by the field test firstly transcribed from the audio tape recording. Then the transcription copy was translated into English. The field test helps the researcher to make the plan on how the ways can be for collecting data, how a question can be asked on different ways and what can be the probing question to find out the participant's actual response on the event. The questionnaire was both in English and Bengali {APPENDIX-7 (English) and APPENDIX-8 (Bengali)}.

3.7. Ethical considerations

Ethical considerations were implemented to avoid ethical problems. Researcher was granted permission from research supervisor and head of the department {APPENDIX-1} from the Department of Occupational Therapy of Bangladesh Health Professions Institute (BHPI), an academic institute of the CRP to conduct the study. Then the researcher will take permission from the head of the occupational therapy department, CRP for collecting data. The ethical considerations were achieved by participant's consent form. Informed consent was obtained by giving each participant a clear description of the study purpose, the procedures were involved in the study and also informing them that they would free to withdraw from the study at any time if they wish. No personal data (e.g. name, address) was recorded to ensure participant confidentiality. Participants were also informed that their information might be published but their name and address would not be used in any way {APPENDIX-4} in the research project to maintain confidentiality. The researcher was committed not to share the information given with others except the research supervisor. These materials will be disposed of after completion of the research project. Recorded data, written data, transcript will be destroyed after six months following the study. Participants also informed that they would not be harmed due to being a participant of the study.

3.8. Materials of data collection

Researcher used a tape recorder to record the conversation or interview with all of the participants during interview time. Audio recording was necessary to develop full transcripts of the interview, which should be accessible to independent analysis (Lowrance, 2006). It was very difficult for researcher to write every questions answer in detail at the time of the interview. Pen, pencil, paper (white), consent form, questionnaire, clip board and tape recorder were also used to collect the data.

3.9. Data collection procedure

Semi-structured interviews were conducted on the basis of structure consisting of open ended questions that define the area to be explored, at least initially, and from which the interviewer or interviewee may diverge in order to pursue an idea in more detail (Qualitative research methods, 2014). Semi-structured interview were used for this study. The researcher used qualitative methodology and asks pre-set, open-ended questions addressing a variety of issues in relation to find out the perceptions. It is useful because this technique ensures that the researcher obtained all information required, while at the same time gives the participants freedom to respond and illustrate concepts.

Researcher took permission from the Head of the Occupational Therapy Department at CRP for data collection {APPENDIX-2}. At first researcher addressed the subjects and informed them of the study. Then researcher took the opinions of subjects who were interested and confirmed time and date of the interview. The researcher selected a quiet place where participants feel comfort and will be able to give adequate attention during interview. The researcher ensured that nobody was present during the interview time at the interview place. At first the researcher took consent from the participant. Then, researcher spent some time to build rapport with the participant. The interviewer explained the title and aim of the study to gain the trust of the participants. Trust is a very important element during an interview, because if the participants feel uneasy to discuss sensitive issues then they may hide the truth. The questionnaire was based on to explore the perception of the wives of person with SCI about the impacts of SCI on them. Interview was conducted in Bengali so that participants would able to understand easily. The answers were recorded by a tape recorder. The researcher also wrote notes. Time range was approximately 30-40 minutes for each interview.

3.10. Data analysis

The researcher selected Qualitative content analysis (QCA) method to analyze the data. It facilitates the formation of core data through a systematic method of reduction and analysis. The theme of the study was created by systematic reduction and analysis of data. QCA follows three steps (coding, categorizing and generating theme) to show the result of the study. In a short line, it is said that, texts are coded into established categories to support the generation of ideas (Denscombe, 2003).

Qualitative data analysis is a complex process. Content analysis was used to discover themes as it was a common data analysis procedure most often used in qualitative data and based on searching for repeated words, phrases or concepts (Hissong, *et al.,* 2014). At first, it includes systemic organization of the field notes, transcripts of interviews and other associated materials. From this data an understanding of how this addresses the research question is formed. The analysis of the data will began with transcription of the interviews. From data analysis researcher transcribed the entire interview in Bangla from a recorder. Researcher observed the relevant issues related to the study and noted it down. It was then given to two individuals who were competent in English, with the intention that they can transform it separately from Bangla to English. Then the researcher verified the accuracy of the data. The researcher read it several times to recognise what the participant wants to say. Researcher also listened to the audio tape again to ensure the validity of data.

Analysis of the interview data began with content analysis. It involved taking a volume of qualitative material and attempting to identify core consistencies and meanings. Then data was coded into broad categories as dictated by the research question. The researcher identified the coded major themes from each interview during initial category coding. The second stage involved identified information units. Information units are categorised into themes in identifying impacts of SCI on partners of person with SCI. Finally analysis of interview data began by analyzing text from the categorised data and coded themes. Researcher also analysed the key themes based on the literature.

3.11. Rigor

The research was conducted in a rigorous manner. All of the steps in the research process were supervised by an experienced supervisor. The researcher did not try to influence the process by her biases, values or own perspectives during the interview and analysis of data. The researcher will always ask open-ended questions, no leading questions will be asked and researcher would not interrupt the participants during answering the questions. Similarly during data analysis, researcher would not submit according to own perspectives. Data were recorded carefully and researcher accepted the answers of the participants whether negative or positive without giving them any impression. The researcher prepared the transcript from the field notes and audio recording. Then it was written soon after the interview. Initially translation was completed by another two people, then researcher completed the same translation and finally all translations were compared. Researcher checked the translated data several times, so that no information was missed. Notes were handled with confidentiality. In the result section, the researcher did not influence the outcome by showing any personal interpretation.

CHAPTER 4
RESULT AND DISCUSSION

Result and discussion analysed by the facts and figures which were collected from the participant's views and practical experiences. These views and experiences are regarding impacts of SCI on partner. It is found that generally the result and discussion were presented together in one section because this is general practice in reporting on qualitative studies (Hissong, *et al.,* 2014). The objectives of the studies were to identify the physical and psychosocial impact on the wives, to identify the impact on ADL's and to identify the impact on affecting relationship and intimacy.

In this section coding were selected on the basis of participant's views and opinions by which the theme was selected. The findings were described by using the table and also highlighted their interview is a coding basis.

4.1. Summary of data analysis and result

Objectives	Questions	Categories	Themes
1. To identify the physical and psychosocial impact on the wives.	**1, 2, 3, 4**	**Category 1:** Problems of the patients due to SCI.	Person with SCI faces many difficulties due to SCI.
		Category 2: Different problems especially physical problems are faced by the wives due to look after her husband.	Wives of the persons with SCI are facing various physical problems due to handling and managing their husband.
		Category 3: Social and mental problems of the wives.	Wives are facing different kinds of social and mental problems after their husbands' SCI.
2. To understand the impacts of SCI on wives in activities of daily living.	**5, 6**	**Category 4:** Difficulties in performing daily living activities.	Wives are facing difficulties in performing ADL's as well as leisure activities by maintaining previous routine.
		Category 5: Impact on leisure activity of the wives.	
3. To identify the impact on affecting relationship and intimacy.	**7, 8, 9**	**Category 6:** Negative impact on relationship for SCI of husband.	Wives have both positive and negative impacts in their relationship.
		Category 7: Relationship with their father in law's house and relatives.	Wives are experienced different impacts regarding the relationship with the people of her own house and relatives.

4.2. Discussion

Each table describes the interview findings. The tick was given only for those columns where the participants expressed their opinion. Here, “P” indicates the participant. The subscript number 1, 2, 3… 9 used to mention the number of participants.

4.2.1. Person with SCI faces many difficulties due to SCI

SCI changes a person’s life and creates new challenges for everyday life. SCI can occur at any level of the spinal cord. Altered or lost body functions depend on the level of the injury. Changes are also depends on how severely the spinal cord was injured. Damage to the spinal cord can cause changes in movement, feeling, bladder control, or other functions (Paralyzed veterans of America, 2014). Complications of SCI spoil the physical, mental and economical condition of that person.

Person with SCI has different complications after getting injury. SCI causes paralysis in different body part. Bowel-bladder incontinence is another most common complication among complete tetraplegic patients (Adler, 2006). The perceptions of the wives to know about the problems are faced by their husbands were collected through interview are stated below by the coding:

Category 1: Problem of the person with SCI

Coding	P1	P2	P3	P4	P5	P6	P7	P8	P9
Having pain in the body such as in the hand, chest, leg, back	✓			✓		✓		✓	
Paralysis in the upper and lower limb		✓	✓	✓	✓	✓	✓	✓	✓
Sensory disturbances in the different body part		✓		✓	✓		✓	✓	
Absence of bowel and bladder control		✓		✓	✓	✓	✓	✓	✓
Difficulties in eating	✓			✓		✓		✓	
Difficulties in walking		✓	✓	✓		✓	✓	✓	
Presence of edema			✓						
Presence of spasm			✓				✓		

Table-1: Problems are faced by the persons with SCI

All the participant are expressed their view and share their experience in the interview time. They told about their husband's complications due to SCI. The participants individually also added their own physical problems due to handle their husbands.

One of the participants mentioned that-
"There is problem, hands and legs are paralysed, cannot move. He has no sense. I have to do everything such as feeding. He cannot do anything. He cannot say about bowel and bladder".

SCI brings changes the person's life. It reduces person's function such as motor and sensory. He faces difficulties in performing his mandatory activities like feeding, bathing, toileting etc. (Pendleton and Schultz-Krohn, 2013). In this study researcher also found these kind of information about the complications of SCI.

Another participant said that-
"Problem occurred. Pain is present all day. Pain in back, backbone is total paralysed. He does not make sense about his bowel and bladder. This is the problem".

Loses bowel and bladder control is one of the common complications among complete SCI persons. They cannot manage their own bowel and bladder. Sometimes they wet bed and clothes. It can cause skin breakdown and pressure sore. They feel pain in their hand, back, leg and whole body. With spinal cord injury, pain may be acute or chronic. Acute pain may be caused by bruising, broken bones, surgery, or positioning. Chronic pain may be caused by overuse of joints and muscles, or changes in muscles, joints and ligaments (Pendleton and Schultz-Krohn, 2013). From the researcher's observation it has been seen that the most common complication is pressure sore, bowel and bladder problem, psychosocial distress etc. It is noticed that every persons with SCI have face various types of problems either less more. These problems restrict their life.

4.2.2. Wives of the persons with SCI are facing various problems due to handling and managing their husband

Complications of SCI are a serious issue. For these reason they cannot manage their own hygiene, ADL's and others activities. Whose primary caregiver is his spouse; mainly depend on their wives for managing those complications. The burden of care giving most frequently falls on the spouse. Particularly different health issues of the wives arise after SCI. These are- low back pain, hand, shoulder pain, increase blood pressure etc (Young, 2003). Caregiving spouses sometimes ignore or neglect their own health problems and needs. Several studies have found specific health complaints related to caregiving. The participants complained that they have different physical problems such as low back pain, hand pain, neck pain etc. during handling their patients (Weitzenkamp *et al.,* 2007). The perceptions of the wives to know about the physical problems are faced by them were collected through interview are stated below by the coding:

Category 2: Different problems especially physical problems are faced by the wives due to look after her husband

Coding	**P1**	**P2**	**P3**	**P4**	**P5**	**P6**	**P7**	**P8**	**P9**
No problems	✓								
Pain in hand		✓	✓	✓		✓			
Pain in shoulder		✓							
Low back pain		✓	✓	✓	✓			✓	✓
Neck pain				✓		✓			
Pain in whole body						✓	✓		
Breathing difficulties									✓
Formations of Excessive fluid in body							✓		

Table-2: Problems are faced by the wives of persons with SCI

One participant complained that-

"Sometimes I feel sick. That means I feel pain in lower back and shoulder".

Low back pain, hand pain, shoulder and neck pain, high blood pressure, heart disease have been linked to caregiving by wives of men with SCI. Hypertension, tingling of extremities, knee pain, and joint pain are seen among the wives if the husband has absence of bowel and bladder control and sensory (Weitzenkamp *et al,*. 2007).

Another participant said that-

"There is problem. I have pain in my hands, neck and whole body. I handle him. He cannot do anything by his own. I have to pull him for side lying and supination. All are done by me."

Disability had negative impacts on the QOL and health of carers, both in the period immediately post injury and across the lifespan. The impact was particularly profound for carers of people with SCI (Gething *et al.* 2006). Wives of the SCI, work as caregiver. The duration of caregiving negatively affect the physical function. The duty of caring for a patient with a chronic disease can increase one's levels of fatigue and result in a lower QOL. The pressure of the burden can impact the physical health of the caregivers. It causes problems like mechanical back pain and knee osteoarthritis as well as having a lower general health condition. These problems can cause limitations for the wives (Ebrahimzadeh *et al.*, 2013). In this study participants also complained different issues such as breathing difficulties, swelling in body. Among those participants only one had no complain about her physical condition. It can be concluded that most of the wives face various types of physical problems.

4.2.3. Wives are facing different kinds of social and mental problems after their husbands' SCI

Frequently mentioned emotional issues include loss, loneliness, and isolation. In one study 60% of spouses expressed feelings of loneliness. They have decreased social contacts. Depression and worries are pervasive, among spouses. Overt depression, feelings of uselessness and of not being understood, and insomnia are seen among them. It is also seen in nondisabled spouses, depression is even greater than that of their own partners. They have also tension about how to manage money for continuing family (Weitzenkamp *et al.*, 2007). 36.1% caregiver is spouses and 68.8% are housekeepers which enabled them to dedicate enough time to their patients. Spouses of the injured people cannot maintain their family as before. They have to stay beside their husbands (Otaghsara *et al.*, 2014). In Bangladesh there is no proper health insurance system. The people who live in the rural area do not aware about it. As a result they become very worry after injury of only earning member.

Category 3: Social and mental problems of the wives

Coding	**P1**	**P2**	**P3**	**P4**	**P5**	**P6**	**P7**	**P8**	**P9**
No problem	✓		✓						
Worries		✓				✓	✓		✓
Worries about how to maintain family		✓		✓	✓	✓	✓		
Worries about money management				✓				✓	✓
Mental pressure				✓					
People in the society gives blame						✓			

Table-3: Social and mental problems are faced by the wives of the persons with SCI

One of the participants explained that-

"I have tension that what would I do in home. How can I take release from here by paying bill? How can I earn money to feed my husband, how can I grow up my child? These tensions are in my mind. I am always worried about my husband and my child."

Main thinking of a wife is about the injured person, who is only one earning member family member. Injured person needs care, so the wife has to think how much care will be needed, how she will pay for the medical expenses and what will lives will be like since the injury occurred. The feelings brought out by a traumatic event such as SCI are thought to be similar in some ways to those experienced when a family member dies. While the wives will be experienced many different feelings about new situation, they begin to deal with what has happened (Jaworski and Richards, 2008). It is also found in this study that a wife of the SCI person has worries about maintaining family, children, medical expenses etc.

Another participant stated that-

"People always tell. Different people say many things. Allah did it. People said different things. I have worriedness. My children stay at home. I stay with my husband. For these reason it is tension, worriedness. It obviously comes, if I don't want."

In a study of Gething *et al.* (2006) there is a considerable impact of caring on psychosocial adjustment. This study reported that the majority of spouses experience high levels of stress as a result of caring. Feelings of helplessness were stated in this study by many spouses, as were depression, loss of independence, guilt over neglecting other family members and physical strain. While spouses try to improve the QOL of their patients with SCI through intensive care, their own QOL may deteriorate (Unalan *et al.*, 2001). Many of the participants reported feeling the brunt of SCI almost immediately after it occurred. A number of anxieties and uncertainties were reported, most of which were associated with the prolonged rehabilitative period.

As psychological issues play an important role in this situation. Frequency of depression and anxiety has effects on the spouses. They reported that caregiving can have a negative effect on the mental health of these persons and depression and anxiety are highly prevalent among them. With regards to caring for children, the difficulties are greatest when the children were very young because certain task such as look after their children is more demanding for the partner with SCI. In contrast, the parent of person with SCI could more easily become involved in certain activities related to the children's upbringing, particularly helping with homework (Beauregard and Noreau, 2009). Spouses of individuals with SCI have a lower QOL and experience greater psychological stress. Previous reports have revealed that poorer caregiver outcomes were associated with lower education and being female (Otaghsara *et al.*, 2014). Lower mood function in the spouses of persons with SCI is very common.

4.2.4. Wives are facing difficulties in performing ADL's as well as leisure activities by maintaining previous routine

The majority of housework appeared to be carried out by the spouse of the person with SCI such as meal preparation, home maintenance, etc. These extra tasks could lead to feelings of burden, especially due to the tasks' relapse. The impact on leisure has also found among the non-injured spouses. These limitations primarily occurred when the spouse had a complete injury and had to rely on a wheelchair for mobility. Because, they cannot move and transfer alone, cannot manage their bowel and bladder. For these reason they rely on their spouses (Beauregard and Noreau, 2009).

Partners of persons with SCI cannot manage their ADL's due to look after their injured husband. The perceptions of the wives about the impacts of SCI on their own daily living activities were collected through interview.

Category 4: Difficulties in performing daily living activities

Coding	P1	P2	P3	P4	P5	P6	P7	P8	P9
Perform after taking care of husband	✓			✓				✓	
Sometime faces problems		✓					✓		
Difficulty to maintain routine			✓		✓	✓		✓	✓
Have to work faster than before					✓				

Table-4: Problems in ADL's are faced by the wives of the persons with SCI

All participants answered from their own perspective about their ADL's and leisure. They explained different problems due to their husband's injury. They always face difficulties in managing ADL's such as eating, bathing, cooking as well as participation in leisure.

One participant said that-

"I cannot do anything timely. Now I am busy with him. Such as- he wets his bed, wants to seat, wants to go to side lying position. He has problem in lying position, pain, and pressure sore. For these reason I have to stay beside him."

Certain persons with SCI (mainly those with tetraplegia) need assistance with personal care such as getting dressed, transferring to bed, showering, and bowel and bladder care. The statements of participants it showed that this task could lead to burnout, especially when combined with other domestic tasks. Here, again, the intensity and frequency of the task could lead to feelings of burden (Beauregard and Noreau, 2009). Spouses have to face difficulties to maintain ADL's of their own after taking care of their husbands. They cannot perform according to previous routine. Different tasks like- cooking, bathing, grooming, eating etc.

A participant of this study stated that-

"I cannot perform my activities appropriately. I am always busy with him. I take my bath one day, but it misses for two days. I am continuing as like this. I cannot eat properly."

Another participant explained her own point of view as-

"Problems must occur. I cannot perform properly. I cannot do timely."

Women, who engage themselves in caregiving of their husband, sometimes try to make balance among their activities. Often they find it difficult to focus on positive aspect if negative reactions are seen. While they want to focus on their own activities it interrupts their caregiving (Reinhard *et al.*, 2014). Wives have responsibility is take care of their husband and to maintain their husband ADL's. They have to perform their own activities and husband's activities together. From the perceptions of the researcher, most of the Bangladeshi wives try to engage themselves in husbands care. They think that it is the most important duty to their husband. They dedicate their life for her husband, children and family. They forget about their own need of eating, bathing, grooming etc. From the perceptions of the participants the researcher found that wives of the tetraplegia SCI have many problems. These are - some wives manage their ADL's after taking care of their husband, some cannot perform according to routine, some have to complete tasks as quickly than before.

Category 5: Impact on leisure activity of the wives

Coding	**P1**	**P2**	**P3**	**P4**	**P5**	**P6**	**P7**	**P8**	**P9**
Perform as like before		✓		✓				✓	
Difficulty in performing leisure activity	✓						✓		
Does not maintain time for leisure			✓	✓	✓	✓		✓	✓

Table-5: Problems in leisure are faced by the wives of the persons with SCI

People might have stopped participating in certain activities that are usually done for recreation or leisure. Most leisure-related difficulties were due to obstructed access to leisure, due to different problems experienced by the partner with SCI. Difficulties could also arise due to handling and look after the patients (Beauregard and Noreau, 2009). All participants shared their own perceptions.

One of the participants said that-

"I do not get time to pass my leisure. I am always busy with him. I do not get time to do these."

The spouses who are always busy with taking care of their husband they cannot pass their leisure activities. They have to be concerned about her husband that when her husband needs help, when needs to change clothe. They are also anxious about the situation. The spouse does not get enough time to enjoy recreational activities due to look after their husband.

Another participant expressed her opinion as-

"I cannot do anything during leisure period. Always stay beside him. I have to stay with him during leisure. I cannot do my own activities. I cannot do any activity as like before."

The spouses do not manage time for their recreation. They don't get enough time to pass leisure time as like before. For these reason the spouses feel monotonous sometimes. Among the all participants there are only few people said that they can perform their recreational as like before and few people sometimes face difficulties. Overall, from the interview it can be said that wives of the persons with SCI have difficulties in their ADL's and leisure. It has negative impacts on their ADL's.

4.2.5. Wives have both positive and negative impacts in their relationship

In a study of Garrett (2012) it was identified that, psychological and emotional changes is common in changing affective relationship, resulting from the injury. These changes are identified as either negative or positive. Ebrahimzadeh *et al.* (2013) stated that, SCI can cause a heavy burden for caregiver spouses due to make a strong emotional tie with the SCI patient. In this study it was observed that, as caregivers expressed their powerful connection to their patients to be the main reason of continuing their duty. Married couples with SCI were not more unstable, had similar dyadic adjustment and marital satisfaction, appear to be more cohesive than able-bodied couples. Distressed couples with SCI tend to express more dissatisfaction with their relationship and more negative communication during conflict resolution (Fisher *et al.*, 2002). From the spouse's perspective, the presence of disabilities had no impact on the feelings of love due to the injury of their husbands (Beauregard and Noreau, 2010). Kreuter (2002) reported that, care giving often changes the balance of power in the marriage partner relationships seem to be impacted by SCI. The researcher found some answers from the all participants regarding difficulties in their relationship due to SCI of their husbands:

Category 6: Positive or Negative impact on relationship for SCI of their husband

Coding	**P1**	**P2**	**P3**	**P4**	**P5**	**P6**	**P7**	**P8**	**P9**
Sometime faces problem	✓			✓					
Always faces problem	✓			✓				✓	
No problem		✓			✓	✓	✓		✓
Better than before			✓						

Table-6: Impact on relationship after SCI of husband

Two of the participants stated that-

"I have no problem in our relationship. It is as like before."

And

"We never quarrel. Our relationship is good."

The impact of the affective relationship of individuals with SCI is positive. The wives have fear of abandonment, separation between the couple. These are negative aspects that arose within the relationship as a result of the traumatic event (Kreuter, 2000). The vast majority of people assumed that, due to injury, there were changes in their affective relationship. Minority revealed that the relationship remains normal, without any impact. There was another finding that, an increase of intimacy provides a range of valued aspects on the couple (Garret, 2012). In this study the majority of participants appeared to accept their husband's situation whereas another study found he negative impact in relationship. This acceptance seemed to be that they are satisfied with their relationship.

Another participant said that-

"I have no problem in our relationship. It is better than before."

The emotional qualities of the SCI person's relationship exist due to the injury of husband. Some of women felt that their partner's injury had resulted in some positive changes. Most of the wives thought they were able to have open and honest communication and they were satisfied with their relationship (Kreuter, 2000). In this study, the researcher got different answers from different participants. Most of them said that they have normal relationship with their husband. Some said they have little bit problem and one participant said her relationship became better. Overall, it can be said that there are both positive and negative impact on relationship after SCI.

4.2.6. Wives are experienced different impacts regarding the relationship with the people of her own house and relatives

Relatives are important supports for the persons with SCI and their family. The shock of the injury influenced families and social networks. Relatives, friends, and even neighbors were affected and tried to give contribution in different ways. This could make an important difference to the partner's situation. The support was also very concrete because the partner spent so much time in hospital. Especially, if the partner also had children to take care of, friends and relatives could be a significant resource (Angel and Buus, 2011). The level of family activities, and blaming oneself for the injury were the three most important variables determining life satisfaction in people with SCI. Many factors affect family relationships, including the presence of depression, suicidal ideation or attempts, and cultural factors. Some of these factors are ameliorated by development of independence, behavioral changes, and a sense of hope (Beauregard and Noreau, 2009). The perceptions of the wives to know about the problems related to their father-in law's house and relatives were collected through interview and stated below-

Category 7: Relationship in their father in law's house

Coding	P1	P2	P3	P4	P5	P6	P7	P8	P9
Doesn't have communication	✓			✓			✓		
Does not get help financially	✓			✓	✓			✓	
Sometimes maintain communication		✓							✓
Does not face any problem			✓			✓			

Table-7: Impact on relationship with father-in-law's house

All the participant are expressed their view and share their experience in the interview time. They stated their opinions.

One participant stated that-
"People of my father-in-laws house took news before, but now they don't take news. They don't help me financially."

Often families tend to cope by over emphasising attitudes and responsibilities which were existed before their family member was injured. Old patterns of behavior do not work given the new family situation introduced by the SCI. The role of each family member may have to change to accommodate the person who is injured (Jaworski and Richards, 2008). Most of the cases the people of the father-in-law's house do not maintain their responsibilities.

Another participant said that-
"Nobody from my father-in-law's house takes news or helps me."

There are no related article wherever describes the problems in the father-in-law's house due to husband's injury. The researcher found from interview that most of the wives don't have communication with the people of father-in-law's house. They do not get any financial or mental support from there. It makes burden and negative impact on them. The perceptions of the wives to know about the problems related to their father-in law's house and relatives were collected through interview and stated below-

Category 8: Relationship with relatives

Coding	**P1**	**P2**	**P3**	**P4**	**P5**	**P6**	**P7**	**P8**	**P9**
Does not face any problem	✓	✓	✓		✓	✓			
Faces problem such as does not have communication				✓			✓	✓	
Relatives give blame				✓				✓	
Pressurize to return money				✓			✓		✓

Table-8: Impact on relationship with relatives

One participant explained that-
"My relatives take news of us. They phone me."

The relatives are so affected that they instead of supporting the partner themselves reached out for support from the partner. This could be experienced as an additional burden (Angel and Buus, 2011).

Another participant stated that-
"Relatives are angry with me. Nobody call me including brother and sister. If I want money, so they do not come. They do not ask anything."

Though there is stated that, in some cases wives of persons with SCI has to face difficulties with relatives. The relatives do not maintain communication, don't help financially, but in this researcher found that most of the wives do not face any problems. Some of them face little problem. Overall, it is found that the wives of persons with SCI face difficulties such as discrimination and negligence in their father-in-laws house and relatives. Wives of the person with SCI are stigmatised by the relatives. They also pressurized to return money which was taken for the treatment of their husband. On the other hand, majority stated that they do not face problems in with their relatives.

CHAPTER 5
LIMITATIONS AND RECOMMENDATIONS

5.1. Limitations

There are some limitations which were unconditionally taken by the researcher into account during the study period. The researcher always tried to consider the limitations during the period of study. These are given below:

- Participants were collected only from CRP. Researcher could not collect information from community setting.
- Researcher could not use quantitative method due to time limitations because it needs more participants than qualitative design. It is time consuming to collect data from many participants.

5.2. Recommendations

5.2.1. Recommendations for Occupational therapist (OTs)s in Bangladesh

OTs should implement a broader role and holistic treatment techniques for the wives of the persons with SCI. OTs need to update their knowledge in this area. OTs should involve the partners in treatment to reduce physical, mental, and social strain. OTs needs to concentrate more on this issue during the treatment period. If the OTs do not involve the partner in their treatment, it would not be significant. For these reason it is necessary to involve the partner in different management program such as-energy conservation techniques, coping strategies, exercises etc.

5.2.2. Recommendations for further research

The researcher's recommendation is that OTs needs to study this topic in depth. This may involve:

- To use quantitative cross-sectional study.
- To collect data from community settings.
- To find out the impacts of SCI on the husbands of female SCI patient.
- The other health professionals can contribute to minimize the vulnerable situation of the partners by providing proper education, patient handling training, and counseling, information for maintaining own health, and promoting social participation.

CHAPTER 6
CONCLUSION

SCI is a life threatening event. It creates harmful effects on individual and their family. Wives of the persons with SCI also become the victims after husbands' injury. Wives play a significant role in caregiving. The wives faced difficulties during providing a high level of care and support to their injured husband. In this study maximum participants faced physical and psychosocial problems. They also have difficulties in the ADL's, relationship and family life.

Wives may seek support from family and relatives, community support groups, professional services, respite and spiritual or religious groups. Family support is particularly important for the wives who care for an individual with SCI (Boydell, *et al.*, 2013).

In Bangladeshi culture the people with SCI are more hospitable. Wives think that caring for their near ones is their responsibility. They take this responsibility enthusiastically rather than feel burden. Appropriate advice and support may preserve caregiving which eventually enables the survivors to live a longer and more fulfilling life in the community.

The OTs has an important role to understand the partner's situation and promote a better social and psychological support for QOL of wives and the SCI survivors as well.

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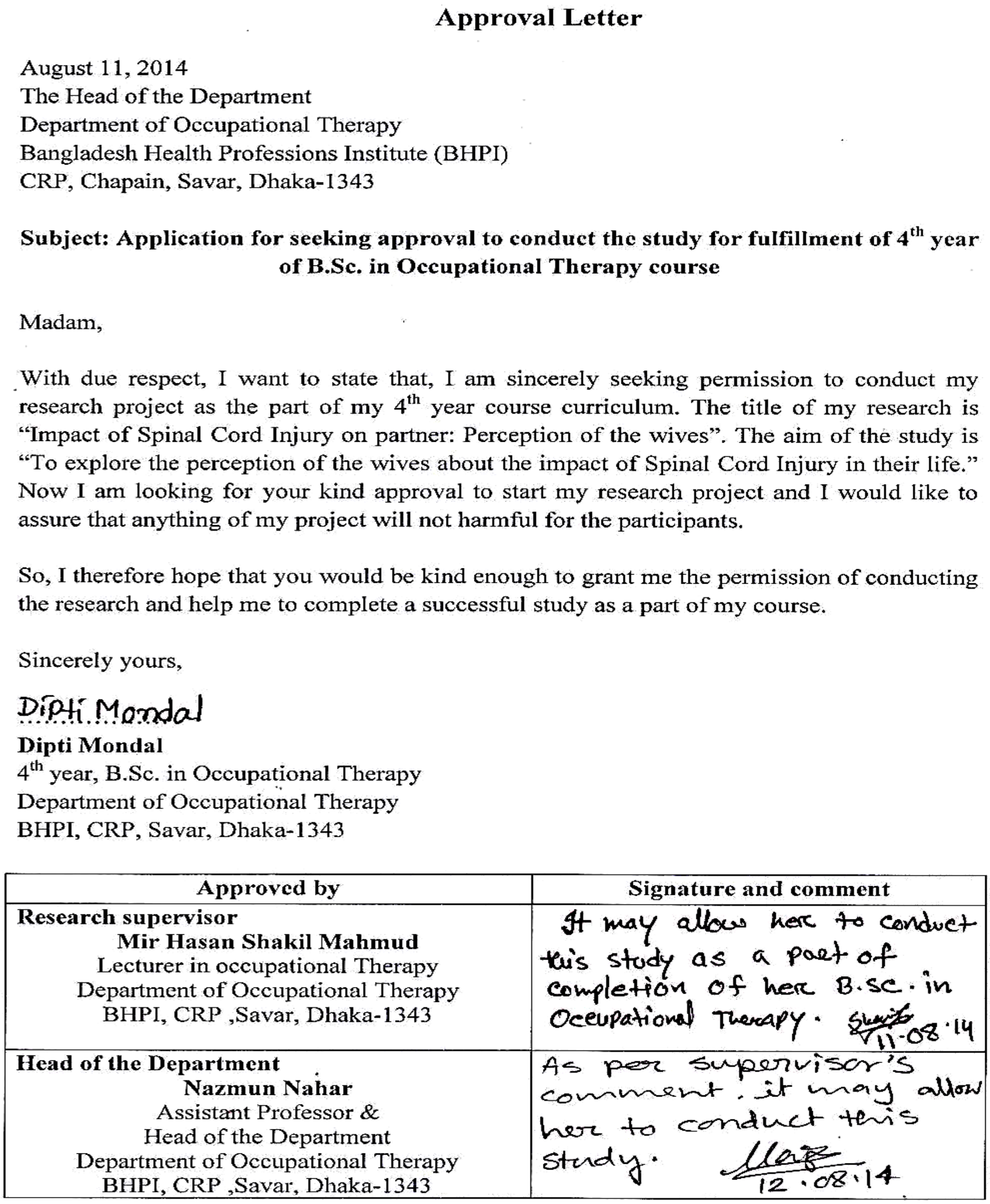
APPENDIX-1

Approval letter for conducting research



Approval Letter

August 11, 2014
The Head of the Department
Department of Occupational Therapy
Bangladesh Health Professions Institute (BHPI)
CRP, Chapain, Savar, Dhaka-1343

Subject: Application for seeking approval to conduct the study for fulfillment of 4th year of B.Sc. in Occupational Therapy course

Madam,

With due respect, I want to state that, I am sincerely seeking permission to conduct my research project as the part of my 4th year course curriculum. The title of my research is "Impact of Spinal Cord Injury on partner: Perception of the wives". The aim of the study is "To explore the perception of the wives about the impact of Spinal Cord Injury in their life." Now I am looking for your kind approval to start my research project and I would like to assure that anything of my project will not harmful for the participants.

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

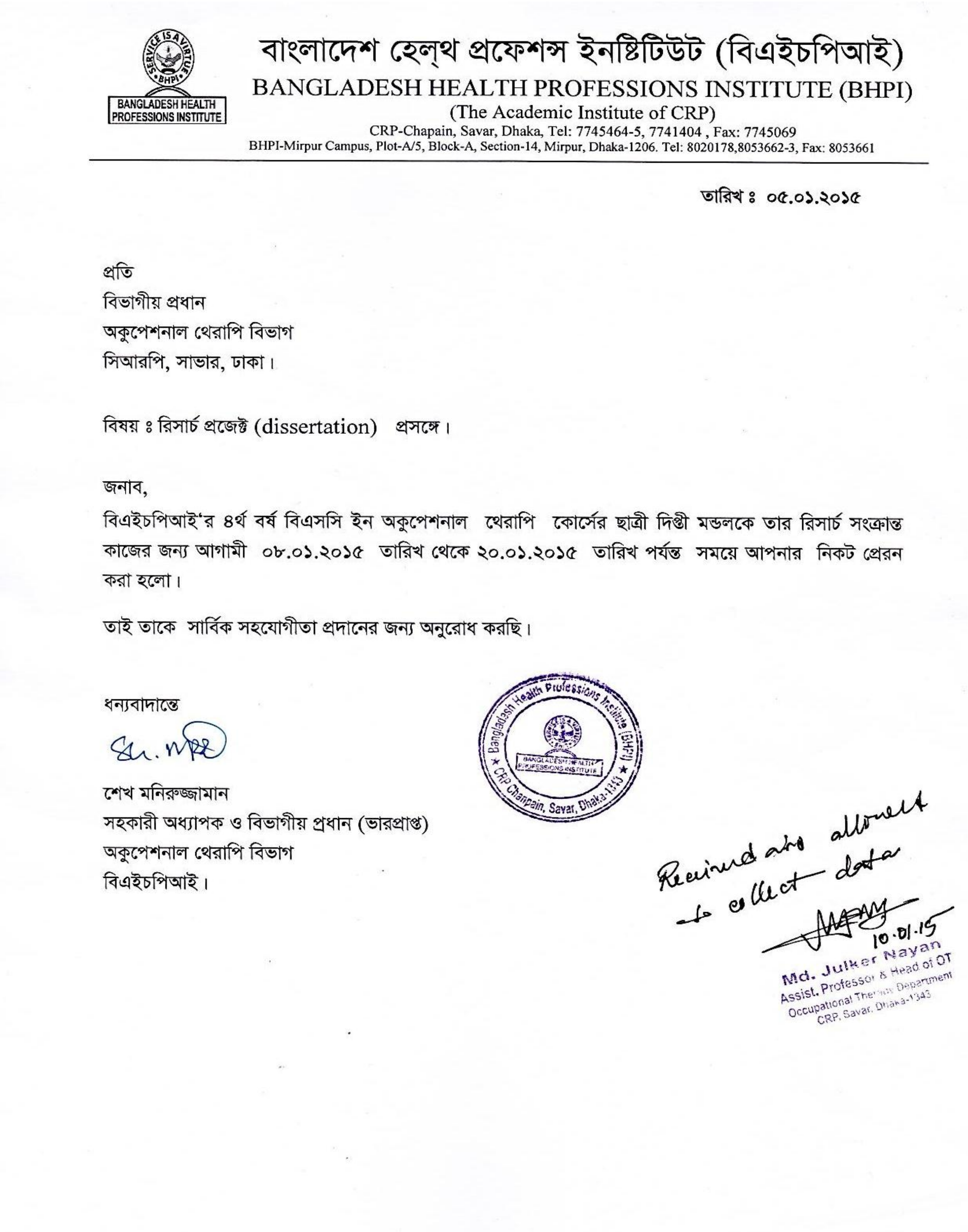
Sincerely yours,

Dipti Mondal
Dipti Mondal
4th year, B.Sc. in Occupational Therapy
Department of Occupational Therapy
BHPI, CRP, Savar, Dhaka-1343

Approved by	Signature and comment
Research supervisor **Mir Hasan Shakil Mahmud** Lecturer in occupational Therapy Department of Occupational Therapy BHPI, CRP ,Savar, Dhaka-1343	It may allow her to conduct this study as a part of completion of her B.Sc. in Occupational Therapy. 11.08.14
Head of the Department **Nazmun Nahar** Assistant Professor & Head of the Department Department of Occupational Therapy BHPI, CRP ,Savar, Dhaka-1343	As per supervisor's comment. it may allow her to conduct this study. 12.08.14

APPENDIX-2

Permission letter for data collection



বাংলাদেশ হেল্‌থ প্রফেশন্স ইনষ্টিটিউট (বিএইচপিআই)
BANGLADESH HEALTH PROFESSIONS INSTITUTE (BHPI)
(The Academic Institute of CRP)
CRP-Chapain, Savar, Dhaka, Tel: 7745464-5, 7741404 , Fax: 7745069
BHPI-Mirpur Campus, Plot-A/5, Block-A, Section-14, Mirpur, Dhaka-1206. Tel: 8020178,8053662-3, Fax: 8053661

তারিখ ঃ ০৫.০১.২০১৫

প্রতি
বিভাগীয় প্রধান
অকুপেশনাল থেরাপি বিভাগ
সিআরপি, সাভার, ঢাকা।

বিষয় ঃ রিসার্চ প্রজেক্ট (dissertation) প্রসঙ্গে।

জনাব,

বিএইচপিআই'র ৪র্থ বর্ষ বিএসসি ইন অকুপেশনাল থেরাপি কোর্সের ছাত্রী দিপ্তী মন্ডলকে তার রিসার্চ সংক্রান্ত কাজের জন্য আগামী ০৮.০১.২০১৫ তারিখ থেকে ২০.০১.২০১৫ তারিখ পর্যন্ত সময়ে আপনার নিকট প্রেরন করা হলো।

তাই তাকে সার্বিক সহযোগীতা প্রদানের জন্য অনুরোধ করছি।

ধন্যবাদান্তে

শেখ মনিরুজ্জামান
সহকারী অধ্যাপক ও বিভাগীয় প্রধান (ভারপ্রাপ্ত)
অকুপেশনাল থেরাপি বিভাগ
বিএইচপিআই।

Received and allowed
to collect data
10.01.15

Md. Julker Nayan
Assist. Professor & Head of OT
Occupational Therapy Department
CRP, Savar, Dhaka-1343

APPENDIX-3

Information Sheet

The name of the researcher is Dipti Mondal. She is the student of 4th year, Department of Occupational Therapy, Bangladesh Health Professions Institute (BHPI). As a part of her academic issues, she has to conduct a dissertation in this academic year. So researcher would like to invite you to participate in this study. The title of the study is **"Impacts of Spinal Cord Injury on partners: Perception of the wives".**

Your participation is voluntary in the study. You can withdraw your participation in anytime. There is not the facility to get any pay by this participation. The study will never be any harm to you but it will help the service user to know your experience, which is very important for the service provider to plan for their future activities. It will also be helpful for the forthcoming caregiver/ partner.

Confidentiality of all records will be highly maintained. The gathered information from you will not be disclosed anywhere except this study and supervisor. The study will certainly never reveal the name of participants.

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

Dipti Mondal
Student of 4th year
B.Sc. in Occupational Therapy
Department of Occupational Therapy
Bangladesh Health Professions Institute (BHPI),
Centre for the Rehabilitation of the Paralysed (CRP),
Chaplain, Savar, Dhaka-1343

APPENDIX-4[*]

তথ্য পত্র

গবেষণাকারীর নাম দীপ্তি মন্ডল। সে বাংলাদেশ হেলথ্ প্রফেশন্স্ ইনস্টিটিউটের (সিআরপির শিক্ষা প্রতিষ্ঠান) অকুপেশনাল থেরাপি বিভাগ এ ৪র্থ বর্ষে অধ্যয়নরত। তার প্রাতিষ্ঠানিক কার্যের অংশ হিসেবে চলন্ত শিক্ষাবর্ষে আমাকে একটি গবেষনা মুলক কাজ করতে হয়ে যার শিরোনাম “সঙ্গীনির উপর স্পাইনালকর্ড ইনজুরির প্রভাবঃ স্ত্রীদের মতামত”।

গবেষনায় আপনার অংশগ্রহন সম্পূর্ণ রুপে স্বেচ্ছায়। আপনি যেকোন সময় গবেষনায় আপনার অংশগ্রহন করা থেকে বিরত থাকতে পারবেন। এই গবেষণায় অংশগ্রহনে গবেষক আপনাকে কোনভাবে আর্থিক সাহায্য প্রদানে অপারগ। এই অংশগ্রহন কখনোই আপনার জন্য ক্ষতির কারণ হয়ে দাঁড়াবেনা কিন্তু এই গবেষনার মাধ্যমে সেবাপ্রদানকারী সদস্যগণ, আপনার অভিজ্ঞতার কথা জানতে পারবেন এবং প্রাপ্ত তথ্য সমূহ সেবার মানোন্নয়নে সাহায্য করবে । এই গবেষণা পরবর্তীতে অন্যান্য শুশ্রষাকরীদেরও ক্ষেত্রেও সহায়ক হবে।

আপনার কাছ থেকে প্রাপ্ত তথ্যসমূহের সর্বোচ্চ গোপনীয়তা রক্ষা করা হবে। গবেষণা এবং গবেষণার সমন্বয়কারী ব্যতীত এই তথ্যগুলো অন্য কোথাও প্রকাশিত হবেনা এবং গবেষণার কোথাও অংশগ্রহনকারীর নাম প্রকাশ হবেনা।

গবেষণা সম্পর্কিত যেকোন ধরনের প্রশ্নের জন্য নিম্নলিখিত ব্যক্তির সাথে যোগাযোগ করার জন্য অনুরোধ করা যাচ্ছে।

দীপ্তি মন্ডল
৪র্থ বর্ষ
বিএসসি ইন অকুপেশনাল থেরাপি
অকুপেশনাল থেরাপি বিভাগ
বাংলাদেশ হেলথ্ প্রফেশন্স্ ইনস্টিটিউট
পক্ষাঘাতগ্রস্তদের পূনর্বাসন কেন্দ্র (সিআরপি)
চাপাইন, সাভার, ঢাকা-১৩৪৩ ।

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[*] Translated Copy

APPENDIX-5

Consent Form

This research is part of Occupational Therapy course and the name of the researcher is *Dipti Mondal.* She is a student of Bangladesh Health Professions Institute (BHPI) in B.Sc. in Occupational Therapy in 4th year. The study was entitled as **“Impacts of Spinal Cord Injury on partners: Perception of the wives.**” The aim of the study is to explore the perception of the wives about the impact of Spinal Cord Injury in their life.

In this study I am ………………………………………………………. a participant and I have been clearly informed about the purpose and aim of the study. I will have the right to refuse in taking part any time at any stage of the study. I will not be bound to answer to anybody. This study has no connection with me and there will be no impact on me and my patient regarding treatment at present and in future.

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

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

APPENDIX-6[*]

সম্মতিপত্র

এই গবেষণাটি অকুপেশনাল থেরাপির একটি অংশ এবং গবেষণাকারীর নাম দীপ্তি মন্ডল।সে বাংলাদেশ হেলথ্ প্রফেশন্স্ ইনস্টিটিউটের অকুপেশনাল থেরাপি বিভাগ এর ৪র্থ বষের্র ছাত্রী। এই গবেষনাটির শিরোনাম “সঙ্গীনির উপর স্পাইনালকর্ড ইনজুরির প্রভাব: স্ত্রীদের মতামত”।

এই গবেষনাতে আমি একজন অংশগ্রহনকারী এবং পরিষ্কারভাবে এই গবেষনার উদ্দেশ্য সম্পর্কে অবগত। আমার যেকোন সময়ে এই গবেষনা থেকে নিজেকে সরিয়ে আনার অধিকার আছে। এজন্য আমি প্রশ্নের উত্তর প্রদান করার জন্য করোকাছে দায়বদ্ধ না। এই গবেষণাটির সাথে আমার কোন সম্পৃক্ততা নেই। আমি আরও অবগত আছি যে, এই কথোপকথন থেকে নেওয়া সমস্ত তথ্যাবলি নিরাপদে এবং গোপন রাখা হবে। আমার নাম এবং ঠিকানা কোথাও প্রকাশ হবে না। শুধুমাত্র গবেষণাকারীর এবং তার গবেষণার সমন্বয়কারীর সাথে এই গবেষণার পদ্ধতি সম্পর্কে অথবা যে কোন প্রশ্নের উত্তর জানার জন্য কথা বলতে পারব।

আমি উপরোক্ত তথ্যগুলো ভালোভাবে জেনে নিজ ইচ্ছায় এই গবেষনায় অংশগ্রহন করছি।

অংশগ্রহনকারীর স্বাক্ষর/টিপসই	তারিখঃ
অংশগ্রহনকারীর স্বাক্ষর	তারিখঃ
সাক্ষ্যপ্রধানকারীর স্বাক্ষর/ টিপসই	তারিখঃ

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[*] Translated copy

APPENDIX-7

Questionnaire

1. Does your patient face difficulties after SCI? Yes/No. Please explain your opinion.
2. Do you face any problem due to look after your husband? Yes/No. Please explain.
3. Do you face any physical problem due to look after your husband? Yes/No. Please explain.
4. Do you face any social and mental problem due to look after your husband? Yes/No. Please explain.
5. Do you have any difficulties in performing daily living activities due to look after your husband? Yes/No. Please explain.
6. Is there any impact on your leisure activity due to look after your husband? Yes/No. Please describe.
7. Is there any negative impact on your relationship for SCI of your husband? Yes/No. Please explain.
8. Do you face any problem in your father in law’s houseafter your husband’s SCI? Yes /No. Please explain.
9. Do you face any problem with your relativesafter your husband’s SCI? Yes /No. Please explain

APPENDIX-8[*]

গবেষণার প্রশ্নাবলী

অংশগ্রহণকারীর নামঃ .... ঠিকানাঃ....................

বয়সঃ .... পেশাঃ ....

১। মেরুজ্জুতে আঘাত পাওয়ার পর থেকে আপনার রোগীকে কি কোনোধরনের সমস্যারসন্মুক্ষীণ হতে হচ্ছে? হ্যা/না। অনুগ্রহকরে আপনার মতামত ব্যাখা করুন।

২। স্বামীকে দেখাশুনা করার ফলে আপনার কোনধরনের সমস্যা হচ্ছে কি? হ্যা/না। অনুগ্রহকওে আপনার মতামত ব্যাখা করুন।

৩। স্বামীর দেখাশুনা করার ফলে আপনার কোনধরনের শারীরিক সমস্যা হচ্ছে কি? হ্যা/না। অনুগ্রহকরে আপনার মতামত ব্যাখা করুন।

৪। স্বামীকে দেখাশুনা করার ফলে সামাজিক ও মানসিক কোনধরনের সমস্যা হচ্ছে কি? হ্যা/না। অনুগ্রহকরে আপনার মতামত ব্যাখা করুন।

৫। স্বামীর দেখাশুনা করার ফলে আপনার দৈনন্দিন কাজকর্মে কোনধরনের শারীরিক সমস্যা হচ্ছে কি? হ্যা/না। অনুগ্রহকরে আপনার মতামত ব্যাখা করুন।

৬। স্বামীকে দেখাশুনা করার ফলে বিনোদনমূলক কর্মকান্ড বা অবসর সময় কাটাতে কোনপ্রভাব পড়েছে কি? হ্যা/না। অনুগ্রহকরে আপনার মতামত ব্যাখা করুন।

৭। আপনার স্বামীর মেরুজ্জুতে আঘাত পাওয়ার ফলে কি আপনাদের সম্পর্কের মাঝে কোন প্রভাব পড়েছে কি? হ্যা/না। অনুগ্রহকরে আপনার মতামত ব্যাখা করুন।

৮। আপনার স্বামীর মেরুজ্জুতে আঘাতপাওয়ার পর আপনার শ্বশুরবাড়িতে কোন সমস্যার সন্মুক্ষীণ হয়েছেন? হ্যা/না। অনুগ্রহকরে আপনার মতামত ব্যাখা করুন।

৯। আপনার স্বামীর মেরুজ্জুতে আঘাত পাওয়ার পর আপনার আত্মীয়স্বজনদের সাথে কোনো সমস্যার কোন সমস্যার সন্মুক্ষীণ হয়েছেন? হ্যা/না অনুগ্রহকরে আপনার মতামত ব্যাখা করুন।

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[*] Translated Copy