

**EXPERIENCES OF
MEN WITH PARAPLEGIA TO
ADJUST TO THEIR SEXUALITY FOLLOWING
SPINAL CORD INJURY**

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

The University of Dhaka

BANGLADESH HEALTH PROFESSIONS INSTITUTE (BHPI)

(The Academic Institute of CRP)

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A research project submitted to the medicine faculty of The University of Dhaka in partial fulfilment of the requirements for the degree of Bachelor with Honours in Occupational Therapy.

DECLARATION

I, **Mir Hasan Shakil Mahmud**, have taken all reasonable steps to ensure that any outcome of this research project will not be harmful to participants. All of the sources used in this study have been cited correctly. Any mistakes or inaccuracies are my own.

Signature:

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Dedicated to
My Mother

KEY TO ABBREVIATIONS

SCI- Spinal Cord Injury

BHPI- Bangladesh Health Professions Institute

CRP- Centre for the Rehabilitation of the Paralysed

OT- Occupational Therapy/Occupational Therapist

ADL- Activities of Daily Living

CNS- Central Nervous System

PNS- Peripheral Nervous System

ABSTRACT

The purpose of this study is to explore the experiences of men with paraplegia to adjust with sexuality in their personal lives. The objectives are to find out the challenges men with paraplegia face during performing sexual activity and to identify how they adjust with those challenges to perform sexual activity in their personal lives. The study was a phenomenological qualitative research design to collect in-depth information of participants' perception. Semi-structured, face to face interviews were conducted to collect the data. Purposive sampling was used and six participants who met the inclusion criteria were selected. Most of the participants informed that most common physical challenges in adjusting to sexuality were bowel and bladder incontinence, risk of pressure sore, loss of movement, pain in the lower back and knees as well as psychological challenges. The findings of this study indicate that participants had different techniques to manage these challenges, such as to discover alternative ways to engage in sexual intercourse, maintain appropriate positions and practice new techniques to adjust with the challenges in performing sexual activity. Most of the men with paraplegia reported satisfaction in their sexual lives. The research also indicates that post-injury married SCI men are more satisfied with their sexual lives than those who married prior to the injury. A person with a SCI needs proper adjustment to their sexual life to cope with those challenges. The person living with a SCI has different techniques to adjust but needs to be careful, in order to maintain some control over the consequences of living with a SCI.

Key words: Spinal cord injury, Paraplegia, Sexuality, Sexual adjustment.

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1.1 Introduction

Spinal cord injury affects all aspects of a person's life. New patients with a spinal cord injury (SCI) need to adjust to different physical, social and emotional problems in their life. Physical problems have an adverse effect that can contribute to difficulties in adjustment to a person with a SCI. Sexuality is an important issue that affects people with a SCI's life structure. Sexuality is an important and sensitive issue for human beings. Sexuality constitutes a fundamental part of people's lives, integrating physical, emotional, intellectual and social aspects. After spinal cord injury, people have to adjust within their sexual life. Therapists may not emphasize this sensitive issue enough in during rehabilitation program. If therapists do not deal this issue properly, it affects on a therapist's competence in dealing with particular disabilities. Because sexuality is a precious need for all human beings. It is an important aspect of a married person's life which is essential for improving the quality of life of a person with a SCI (Couldrick 2005, p. 317).

People with a SCI have to adapt with different problems in their sexual lives. They might have many discomforts in their sexual lives including feelings of anxiety, fear as well as physical disabilities, and for that he become frustrated and depressed about their condition. This issue is very sensitive in our socio-cultural aspect. During rehabilitation program an occupational therapist has a role in assisting a person with SCI to adjust and adapt to sexuality post injury, in order to improve total quality of life.

People with a SCI have a right of full intimacy and sexual pleasure as anyone else. The quality of the sexual relationship depends on quality of total care and respect that each partner has for the other. This is an important and essential thing for our human life. So in order to offer better rehabilitation services to the people with a SCI, it is an important issue for conducting researches. This study addressed on the experiences of men with paraplegia to adjust with sexuality in their personal lives.

1.2 Background information

Center for the Rehabilitation of the Paralysed (CRP) is a unique and specialised rehabilitation center in Bangladesh for people with a SCI. The researcher completed clinical placement in the spinal cord injury unit at CRP. Researcher observed that people with a SCI struggle to adjust to the change in situation of their life. Many people survive spinal cord injury in the world. The National Spinal Cord Injury Association Resource Center (1995) reports that there are approximately 10,000 people who survive with a spinal cord injury every year, 80% of those people are male. Spinal cord injury may affect the male's ability for partner conception to be achieved. There are numerous strategies available to help a couple where the man has a spinal cord injury to have children. A couple also needs to adjust to their sexuality in their personal lives. This is very important issue for a couple to know. Researcher was interested to know how men with paraplegia people adjust with sexuality in their personal lives.

Sexuality is an important part of self-image and identity. If people accept that sexual expression is a natural and important part of their life, then perceptions that deny sexuality for people with a disability deny a basic right of expression.

This issue is very sensitive in our socio-cultural aspect. Person with a SCI needs proper guidance about their sexual lives during rehabilitation time. Therapists concentrate on this issue in order to improve quality of life. There are a small number of related studies and resources available about sexuality in a Bangladeshi context. However large numbers of international studies have been done on this topic. Until now, Bangladesh is behind in addressing personal matters like sexuality in comparison to other countries.

1.3 Significance of the study

The researcher explained broadly about the adjustment process of person with a SCI in sexual activities. This study also identified common challenges for a patient with SCI which interfere the participation in sexual activity. Men with a SCI experience changes in their sexual function. In addition to these physical changes, most men also experience emotional changes that often affect their overall sexuality. This is a more insightful issue in our society and culture. Most people in our society tend to hide this

issue. The patient may feel uncomfortable to explore his difficulties with a service provider. It is very important for men and their partners to understand and address these issues as a part of the overall adjustment to life after injury. Moreover, it is easier for the same gender to talk about this sensitive issue than member of the opposite gender. The result of this study can be help to benefit newly injured patients with a SCI.

According to the American Occupational Therapy Association (2002, as cited in Sakellarios & Algado, 2006b), sexuality is an activities of daily living (ADL). Occupational therapists are interested in a client's performance in these ADLs following injury. If an occupational therapist develops their knowledge about sexuality, then they would develop skills in rehabilitation for their client on this topic. Patients may benefit from this type of Occupational Therapy intervention.

Sexuality is a basic fundamental practice of human behavior. This practice is desired and needed for individuals to form relationships with their partner (Yallop 2000, p. 419). The researcher wants to find out the answer within a Bangladeshi, spinal cord injury population.

This study is very important for other health professionals. The focus is on improving quality of life for people with a SCI in their everyday life. It may assist in the development of other professionals such as social worker, counselor and sex educator's knowledge on this topic.

Sexuality is a broad area for study. Not many studies have been done in a Bangladeshi context. In 1988, according to Farman and Friedman (2004, p. 538), a study reported that 88% of 50 Occupational Therapy programs included training about sexual function. Researcher feels much interest in this area, as a student of Occupational Therapy (OT). It is hoped that further resources is developed in this area after completing this study. Patients with SCI, health professionals and also occupational therapists may have more knowledge about the sexuality of a person with a disability.

Finally, from this study patients may benefit following holistic rehabilitation from a practitioner who has gained knowledge from the study.

1.4 Aim of the study

To explore the experiences of men with paraplegia to adjust with sexuality in their personal lives.

1.5 Objectives of the study

- To find out the challenges men with paraplegia face during performing sexual activity.
- To identify how they adjust with those challenges to perform sexual activity in their personal lives.

2.1 Spinal cord

The spinal cord is a long cylindrical structure in the body. It maintains communication from the brain to body. It is slightly flattened dorsoventrally, occupying the upper two-third of the vertebral canal. Spinal cord injury can occur after a non-traumatic or traumatic injury. This may cause disruption in body communication, then resulting in a loss of function.

The spinal cord controls the bladder and bowel, sexual function, blood pressure, skin blood flow, sweating, and temperature regulation (Spinal cord and column information 2003). If any disruption occurs in the spinal cord after traumatic injury, the message can not be transferred below the site of the lesion (Hollar 1995, pp. 795-796), as there is damage the nerve roots of the spinal cord at the site of the lesion. The nerve roots of the spinal cord carry information from the sensory and motor systems. The sensory and motor nerve fibers carry all information between the brain and whole body via the spinal cord. Those nerves work like a telephone cable which carries messages in both directions from the brain to individual muscle spindles and skin and from organs to the brain (Moving forward: the guide to living with spinal cord injury 1995). Seeley, Stephens and Tate (2003, p. 402) discuss that the brain and PNS integrate different information from the body and produce responses through the reflex mechanisms. Spinal cord injury may responsible for interrupting whole body communication.

2.2 Spinal cord injury

Spinal cord injury occurs by non-traumatic injury such as viral infection, cysts, tumours and traumatic injury such as road accident, fall from a high place, sports injury and violence causing damage to the spinal cord. People with a SCI have different types of functional problems.

Spinal cord injury is defined as damage or trauma to the spinal cord that inturn leads to a loss or impaired function resulting in reduced mobility or feeling. As nerve roots are segmental, a thorough evaluation of motor and sensory function can identify the lesion level. Many accidents happen in Bangladesh. SCI is a major health problem in

Bangladesh. Approximately 10% of the whole Bangladeshi population has a disability (Rozario 2003, p. 226).

According to Krause and Crewe (2001); *“Spinal cord injury is a non-traumatic and traumatic injury, which typically occurs suddenly and without warning. It has an immediate impact on all areas of the individual’s physical and psychosocial functioning”*.

After spinal cord injury a person’s sexual function can be affected. Sexual function is controlled by parts of the nervous system (CNS), particularly in the brain and spinal cord. Any interference or cut in the spinal cord through injury will therefore affect the normal sexual response cycle. The impairment will depend on the level of injury, the severity of the injury (complete or incomplete) and the gender of the injured person. Atkins (2002, p. 971) states that SCI directly affects both sexual intercourse and reproduction.

People with a SCI need to adjust with their daily living activities post injury. They also have to adjust with sexuality in their personal lives. McKenna (2003, pp. 543-544) mentioned that many people with a SCI stated that sex was much more intimate and spiritual than it was prior to the injury. Those people have found much pleasure in discovering their own and their partner’s bodies in a new way. After spinal cord injury, sexuality is important and vital issue to address for every person with a SCI. This study discovered the experiences of men with paraplegia to adjust with sexuality in their personal lives.

2.3 Paraplegia

According to the spinal cord injury zone (2008) *“Paraplegia is the loss of sensation and movement in legs and in part or on the trunk, usually resulting from an injury to the spinal cord below the neck”*. Paraplegia refers to loss of sensory and motor function in the thoracic, lumbar or sacral segments of the spinal cord, secondary damage of neural elements within the spinal canal. Paraplegic function depends on the level of injury; the trunk, legs and pelvic organs may be involved (Medical 2003).

Paraplegia can be divided into two types according to the level: high paraplegia and low paraplegia. High paraplegia is referred to spinal cord T₂-T₆ and low paraplegia refers to T₇ to below (Somers 1992, pp. 83-84). The ability level of a person with paraplegia depends mainly upon the level of the injury. For men with paraplegia upper body strength is preserved and they have greater independence than men with tetraplegia in all aspect of their personal lives.

There are two terms used in spinal cord injury: complete and incomplete. According to American Spinal Cord Injury Association (ASIA) 2000, "*Complete injury consists of absence of sensory or motor function in the lowest sacral segment (S₄-S₅)*". The spinal cord is damaged fully through compression, dislocation, rotation, hyperextension, overstretching or a total disruption of the blood supply. The patient has no sensation or movement below the lesion that is described as having a complete spinal cord injury. If the grey matter of the spinal cord dies than the injury is not reversible. "*Incomplete injury should be used only when there is partial preservation of sensory and/or motor function below the neurological level and including the lower sacral segment (S₄-S₅)*" (Atkins 2002, p. 968).

Men with paraplegia have the capability to lead a more independent life using upper body part than people with tetraplegia. For this reason, researcher has selected men with paraplegia in this study.

2.4 Sexuality

Sexuality is a part of human life. It is very important for life satisfaction. It develops throughout life in response to a person's physical, psychological, social and culture. It is also a part of everyday thoughts, feelings, behaviors and relationship. It gives shape in gender identity, contributing to self-esteem and social roles (McKenna 2003, p. 541). It is a basic fundamental as well as an integral part of human life. It can not be seen as a separate aspect of a person. It should be regarded when a person enters into a rehabilitation program because sexuality is an activity of daily living.

Sexuality is important aspect of social life. It is used to form and to maintain relationships, to communicate with a partner and to bolster self-esteem. Sexuality is more than just sexual intercourse. Attire, interaction with others, smiles and reaction

to others are all expressions of sexuality. As is a wide variety of sexual acts (Somers 1992, p. 275).

According to the Taber's cyclopedic medical dictionary (Venes 2001) "*Sexuality is (a) States of having sex and (b) Collective characteristic marking difference between male and female*".

The specific section (health desk) of "The Daily Star (12 July 2008, p. 24)" published this news: *People need physical and emotional intimacy almost as much as they need food and shelter. Sexuality helps fulfill the vital need for human connection. It is a natural and healthy part of living as well as important aspect of identity as a man or woman.* Sexuality develops throughout one's life and is an integral part of everyday thoughts, feelings and behavior. It shapes gender identity, contributes to self-esteem and social role formation and relates to a whole spectrum of attitude, behavior and activities (Sakellariou & Algado 2006, p. 350).

Human sexual response is followed by different phases. According to Freda (1998, pp. 364-366), the sexual response cycle is divided into four phases. The phases are excitement, plateau, orgasm and resolution. Sexual function of the human body is controlled by parts of the nervous system; particularly central nervous system (brain and spinal cord). After SCI people experience a change in their sexual ability and function. In addition to these physical changes, most men also experience emotional issues that often affect their overall sexuality. It is very important for men and their partners to understand and address these issues as a part of the overall adjustment to life after injury. It is also important for health professionals to know about normal sexual function.

2.4.1 Normal male sexual function

Male sexual functioning is a complicated process. Male genital function consists of erection, emission and ejaculation during sexual activity. According Ducharme (2000), erectile and ejaculatory functions are complex physiological activities that require the interaction between the vascular, nervous and endocrine systems.

Erection is a vascular event, occurring when the erectile bodies of the penis become distended with blood. It can be initiated by either parasympathetic or sympathetic

stimulation. Human sexuality is normally presented by two types of erections. They are psychogenic erection and reflex erection. The brain is the source of psychogenic erection. The process begins with sexual thoughts or seeing or hearing something stimulating or arousing. First signals are transmitted from the brain then sent through the nerves of the spinal cord down to the T₁₀-L₂ levels. The signals are then relayed to the penis and trigger an erection. Reflex erection occurs with direct physical contact to the penis or other erotic areas such as the ears, nipples or neck. Reflex erection is involuntary and can occur without sexually stimulating thoughts. The nerves that control a man's ability to have a reflex erection are located in the sacral nerves (S₂-S₄) of the spinal cord (Sexual function for men with SCI 2007).

Following erection, the next stage of normal sexual function is emission. Emission is the process by which semen reaches the posterior urethra in preparation for ejaculation. During emission, peristaltic of the smooth muscle of the vas deferens causes sperm to be transported from the epididymus to the end of the vas deferens. Secretions from the seminal vesicals and prostate are added to the sperm to form semen. Contraction of the smooth muscle of the ampulla, seminal vesicals, and prostate and partial closure of the bladder neck causes the semen to enter the posterior urethra. Neurological control of emission involves the cerebral cortex and both sacral and thoracolumbar spinal cord. Afferents from genitals enter the second through fourth segments of the spinal cord. From there they ascend to the cerebral cortex. Efferents from the cerebral cortex travel via the anterolateral columns to the thoracolumbar cord, T₁₂ through L₃ (Somers 1992, pp. 277-278). The next stage of normal sexual function is ejaculation.

Ejaculation is the process by which semen is propelled from the posterior urethra. It involves contraction of striated musculature. The rhythmic contraction of these muscles, combined with closure of the bladder neck, propels the semen forward and out of the urethra. It occurs as a result of a somatic sacral reflex. Sensory afferents are activated when semen enters the posterior urethra as a result of emission. During ejaculation, the anal sphincter also contracts rhythmically. The ability to ejaculate is controlled by nerves which originate in the lowest part of the spinal cord that is segments T₁₂ to L₂ and S₂₋₄ (Sexuality in spinal cord injury: the spinal cord injured male: ejaculation, orgasm, and coitus 1998).

This is a description of normal sexual function for men. After SCI men's sexual function responds differently. Spinal cord injury can have a great effect on a men's sexual function.

2.4.2 Sexual function of men after injury

Spinal cord injury can affect a men's sexuality both physically and psychologically. The majority of men with spinal cord injury experience some changes in sexual function. The type and level of injury both play a role on the impact their sexuality. After injury, physical changes can include: the inability to attain or maintain an erection (erectile dysfunction), ejaculate or orgasm. Men can also experience emotional changes that can affect their sexuality (Sexual function in patients with spinal cord injury 2008). Men's sexual ability is also an essential part for the continuity of sexual activity.

The ability of a psychogenic erection depends on the level and extent (complete or incomplete) of injury for SCI people. Generally, men who have low level incomplete injuries are more likely to have psychogenic erection than men who have higher level incomplete injuries. Men who have complete injuries are less likely to experience psychogenic erection. However, most men with SCI are able to have a reflex erection with physical stimulation regardless of the extent of the injury if the S₂-S₄ nerve pathways are not damaged. As SCI level lesion is different the impact of the injury on sexual function can also differ.

Another type of common physical problem in some men with SCI is called retrograde ejaculation. Men with retrograde ejaculation release all or part of their semen into their bladder during ejaculation instead of it releasing it through the tip of the penis. Injuries to the spinal cord can sometimes interfere with the function of the internal muscles called spincters, preventing the bladder opening from closing properly. As a result, during ejaculation semen is propelled backward into the bladder instead of leaving the penis. This causes semen to mix with urine in the bladder and leave the body during urination without harming the bladder. Retrograde ejaculation can impair fertility since it affects the delivering of sperm to the vagina during intercourse (Sexual function in patients with spinal cord injury 2008). People with a SCI need to adjust with their sexual lives after the injury.

2.5 Sexual adjustment

Adjustment is defined as adapting to a new condition. Everyone makes adjustment during their lifetime. Some of the conditions that need to be adjusted to may be planned. Post injury people with a SCI have time to think about how they are going to react with the situation. Adjustment is a life-long process. The emotional aspects of disability may be a major factor in determining the outcome and benefits of all rehabilitative efforts (Stages of psychological adjustment to disability 1986). People with a disability need to adjust in all aspects of their lives.

Everyone's adjustment changes with time and circumstances. Parents, family members, partner and individuals with disabilities have similar ways of adjusting with the different condition of their life with disability. The adjustment process is shown in the figure below:

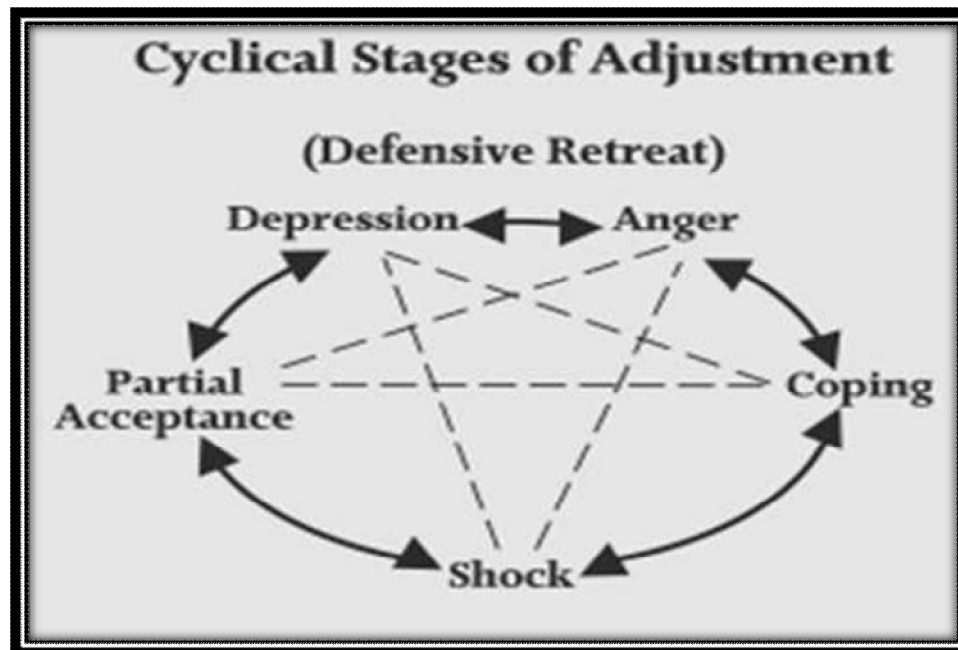


Fig: Stages of Adjustment Process (English 2000, p. 8)

Shock: Shock is the main feeling upon first getting discouraging news related to disability. Shock is very emotional. People who experience shock frequently display

some denial, bargaining behavior and fear related to facing disability realities and implications (English 2000, p. 8).

Partial Acceptance: Partial acceptance is where the person with a disability and their family accept some of the realities related to disability.

Depression and Anger: Depression and anger are parallel ways of emotional hiding. A person with a disability feels threatened and chooses to protect themselves in these stages. A person's anger is turned inwards on themselves and outwards on others. Depression and anger create a hard situation for family members, especially people living together.

A person with a disability affected by depression may have self-pity, be passive and inefficient. Often, depression is likened with grieving. Very depressed people feel worthless, helpless, and hopeless.

A person with a disability who demonstrates anger tends to blame other people and organisations. They may lash out over the unfairness of new limitations and adjustments.

Coping: Coping is the stage of adjustment where a person recognises and accepts certain limitations. Most individuals and families are learning to cope effectively with disability and adapt to changes demanded by reality. Individuals and families who are in the coping stage are able to discover important new strengths that improve their quality of life (English 2000, p. 8).

Before the injury, a person's routine was very familiar and comfortable for him. After the injury, things can suddenly change. Pre and post-injury routines are usually very different, and men who are newly injured will likely face a lot of physical and emotional challenges as they adjust to life after injury. Sometime it takes time to rebuild a life following SCI. After injury, a person learns about SCI and self-care issues such as bowel, bladder and skin care management. Those daily self-care issues are managed. However sex usually becomes a hidden issue of person's life (Sexual function for men with SCI 2007).

Spinal cord injury may cause marked changes on sexual relationships and sexuality. After the injury, the person and their partner need to adjust to the different problems

associated with sexuality (North 1999, p. 675). Sexual adjustment is essential to the overall adjustment to life for men following injury. They may not be able to give or receive proper physical pleasure. They may be experience a loss of self-satisfaction, confidence and self-worth. As time passes, many men with SCI begin to experience a greater appreciation for sexuality. Hopefully, they able to regain any lost feelings of self-satisfaction, confidence, and self-worth as they become more comfortable with their bodies. They often find pleasure in holding hands, hugging and kissing in addition to sexual intercourse. Many men also experience a greater emotional closeness with loved ones (Sexual function for men with SCI 2007).

2.6 Factors affecting sexuality after SCI

Loss of sensation: This is one of the major problems for every person with a SCI. After SCI, the main physiological function of a body is changed. Some of the nerves once counted on to provide pleasurable feelings in sexual organs and other erotic areas are damaged. The person's body may no longer be working as it did before the injury. This may result in the inability to feel pain, temperature changes, pressure or touch over one or several parts of the body. This may greatly affect a person with a SCI's life style (SCI network board n.d.).

Pressure sore: People with a SCI are particularly susceptible to pressure sores because the injury reduces or eliminates sensations. This makes it difficult to know when a sore is developing. Pressure sores can develop in different body surface area when people with a SCI sit or lie in the same position for a long time (Spinal cord injury 2007). Pressure sores cause difficulty in positioning and mobility. This greatly affects a person's sexual life (McKenna 2003, p. 543).

Level of injury: Sexual function is dependent on the level of the injury. A higher level of injury involves paralysis and loss of sensation in both arms and both legs. A lower level of injury involves only the legs. For those people, parts of the upper trunk and the arms have normal sensation and muscle function. In sexual activity, people with low level SCI have more potential than those with a higher level of injury to have an active sexual life (Possible changes in sexuality following spinal cord injury n.d.).

Bowel and bladder incontinence: This is a very uncomfortable situation for the individual person and partner. To avoid this situation the patient might remain on the

same bowel and bladder management schedule. A person with SCI should be advised to avoid drinking excessive fluid before sexual intercourse (Jurisic 1993).

Mobility deficits: Mobility deficits can lead to difficulties in the performance of sexual activity after SCI. This is due to poor muscle power in the affected part of the body (Freda 1998, p. 366).

Muscle spasms: Muscle spasms interfere with sexuality. This is when there is increase muscle tension and involuntary muscle movement. This can increase or decrease sexual pleasure. A couple should try to discover positions that promote or inhibit spasms accordingly (Teaching sex education 2007).

Pain in back/neck: Pain in back or neck may affect in sexual activity. Person with a SCI need back and neck aligned as much as possible and back supported with a firm mattress. It is very important to find out a way to support the neck during oral sex (Teaching sex education 2007).

Other factors: There are some other important factors that affect sexuality directly. Those factors are anxiety, depression, fear, trust, affection and lack of physical or emotional feelings (Freda 1998, pp. 364-368).

2.7 Role of Occupational Therapy in sexuality

Solet (2002, p. 773) discusses that Occupational Therapy (OT) is a holistic health care profession that evaluates and treats the patient in regards to their activities of daily living, including sexual activity.

McKenna (2003, p. 541) states that sexuality develops throughout life person's physical, psychological and social development. It is a part of everyday thought, feelings, behavior and relationships. Sexuality provides gender identity and contributes to self esteem and social role. Illness and disability can affect sexual function. So, OT plays a vital role dealing with sexuality adjustment after having SCI to enhance persons' participation to everyday function.

An Occupational Therapist (OT) is an essential part of a rehabilitation team. Therapist can raise awareness among people with a SCI about their present situation and educate them how to perform safe sexual acts. OT can play the role of a counselor to

deal with anxiety, depression and fear (McKenna 2003). SCI is such type of condition where people face problems in sexual acts after the injury. Literature argues that OT should promote sexual health by working with SCI patients in their professional role in a sexuality affirming way (Couldrick 2005, p. 315).

Role of Occupational Therapy in sexuality includes:

- Addressing sexual issues as an activity of daily living.
- Identification of problems on the basis of different performance in domains of motor, psychological, sensory and cognitive.
- Identification of client's limitations and abilities in sexual activity.
- Provide appropriate training to client and client's partner about ADLs, safety education, psychological and home plan (Farman & Friedman 2004, pp. 337-338).

Sexuality has an inherently occupational element which can be exposed through a variety of occupations such as grooming, dating or having sex. The main role of the OT is to empower their clients and to help them to achieve an individual and meaningful quality of life. OT treats the patient as a whole and directs therapy according to the client's need. This should be the core OT intervention for patients with a SCI.

3.1 Study design

In this study researcher used phenomenological qualitative research design that is descriptive, exploratory and contextual to determine the experiences of men with paraplegia to adjust with sexuality in their personal lives. Phenomenological perspective can be implemented to any study where the investigator is concerned with people's views on their own life or situations, or their own views regarding existing circumstances such as their ill health and how they deal with this problem (Bailey 1997, p. 40).

The study aims to discover the adjustment pattern towards the sexual problems of married men with paraplegia. A qualitative method is suitable to explore this new area. Qualitative approach explores and describes the subjective experiences of the participants (Magenuka 2006, p. 61). Given the exploratory nature of the study, a qualitative methodology was chosen.

A qualitative approach was selected and semi-structured face-to-face interviews were conducted to investigate how men with paraplegia adjust with sexuality. By semi-structured interview, participants obtained autonomy to explain their opinion, to share knowledge from their own point of view. Other literature states that when a researcher wants to find out the research question by seeking the experiences, feelings and performance of the individual, a qualitative research design is appropriate for the study (Hicks 2000, p. 7). By qualitative approach, it is appropriate to gain insights to a person's inspection, judgment, manner and values of their own situation.

3.2 Sampling

The study was a qualitative type of study. The researcher was interested to obtain a complete understanding of the phenomenon by analysing a range of participant's experiences. Subjects were collected by using purposive sampling from the population who met the inclusion criteria. Purposive sampling was used because the researcher did not simply study whoever was available, but used judgment to select a

sample (Frankel & Wallen 2000, p. 114). Samples were selected from different community settings and men with paraplegia who are married. Purposive sampling method is used in qualitative studies to study the lived experience of a specific population. In qualitative studies, the sample size is generally very small (Northern arizona university 1997). The purpose was to examine the experience that has been shared by individuals. Six participants were selected by using purposive sampling to conduct the study. Participants were selected by considering specific selection criteria.

3.3 Inclusion criteria

- Men with a SCI only are participants in the study. Females with a SCI have more potentiality to participate in sexual activity than men with a SCI. Men face more challenges in sexual activity after injury (Somers 1992, p. 288).
- Participants should be men with paraplegia. Men with paraplegia's functional abilities and physical capabilities are better than tetraplegia level SCI. Paraplegic refers T₂ to below (Somers 1992, pp. 83-84).
- Both complete and incomplete SCI patients were included in this study. Male sexual function and ability can change after the injury. Sexual function and ability also depends on complete and incomplete level of injury (Sexual function for men with SCI 2007).
- Men with paraplegia who are married and completed rehabilitation program at CRP. During the rehabilitation time, client and his partner educated about all ADLs, social role, physical needs, emotional needs and all aspects of life as well as participating in sexual activity with his partner (Momin 2003).
- People who have intact speech and cognition because they have to explore their experiences.

3.4 Study settings

Qualitative research design focuses on ordinary events in natural settings. The researcher observes and interacts with the individual in participant's own context (Hammell, Carpenter & Dyck 2000, p. 16). Sexuality is very sensitive issue. Therefore participants need a comfortable environment for discussing this topic. Research collected via interview in the participant's home environment in their own community. Participants have the opportunity to maintain and lead comfortable sexual

lives in their home. Therefore they may achieve better adjustment with sexual problems in their own community.

3.5 Informed consent

To take consent from subjects, researcher developed a consent form in Bangla {APPENDIX- I (a)} and English {APPENDIX- I (b)}. During the interview researcher took permission from each participant with signature on a written consent form of the participants who were interested to take part in the study. Then researcher also took signature of a witness. Researcher clarified the role of the participants in the study and ensured that it did not cause any harm to them and discussed that in future people with paraplegia would benefit from the study. Participants were informed the given information would not be shared with others. Researcher explained to participants how interview data would be used in the study and make sure that their identity remained confidential in the study. Researcher also explained the benefits of the study and their right to decline answering any questions during interview and to refuse to participate in the study at any time.

3.6 Field test

A field test was conducted with two participants. Before beginning the final data collection, it was necessary to carry out a field test to help the researcher refine the data collection plan. During the interview, researcher informed the participants about the aim and objectives of the study. From the field test the researcher became aware about which parts the participants found difficult to understand. However, participant's interviewed data was not analysed because time was limited. Researcher only generalised the situation of the interview, participants' responses and considered whether the data collection was going in the right way. The answers that came out from these selected questions helped the researcher to modify the questions where necessary. This also helped to structure the questionnaire. Finally the questionnaire was developed in Bangla {APPENDIX- II (a)} and English {APPENDIX- II (b)}.

3.7 Ethical considerations

Ethical considerations were implemented to avoid ethical problems. Researcher was granted permission from research supervisor and course coordinator (APPENDIX-III) from the Department of Occupational Therapy of Bangladesh Health Professions Institute (BHPI), an academic institute of the Centre for the Rehabilitation of the Paralyzed (CRP) to conduct the study. The ethical considerations were achieved by participant consent form. Informed consent was obtained by giving each participant a clear description of the study purpose, the procedures 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- IV) in the research project to maintain confidentiality. The researcher also 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 were also informed that they would not be harmed due to being a participant of the study.

3.8 Materials of data collection

During interview time, researcher used a tape recorder to collect the conversation or interview with all of the participants. Audio recording was necessary to develop full transcripts of the interview, which should be accessible to independent analysis (Polgar & Thomas 1991, p.124). It was suitable for the researcher. It would have been 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 are 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: qualitative interviews in medical research 1995). Semi-structured interview was used for this study. The researcher used qualitative methodology and asked pre-set, open-ended questions addressing a variety of issues in relation to adjustment with sexuality. 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 collected the data independently. Researcher collected all participants' addresses from the Social Welfare department at CRP and took permission from the Head of the Rehabilitation division at CRP for data collection (APPENDIX- V). 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. Before data collection, the researcher selected a quiet place where participants felt comfort and were 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 was 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. During an interview, trust is a very important element because if the participants feel uneasy to discuss sensitive issues then they may hide the truth. The questionnaire was based on people with paraplegia to adjust with sexuality in their personal lives. Interview was conducted in Bangla so that participants could easily understand. The answers were recorded by a tape recorder. The researcher also wrote down field notes and facial expressions. Time range was 30-40 minutes for each interview.

3.10 Data analysis

The purpose of the data analysis was to find out the actual meaning of the information that is collected. By using a data analysis process it was easy to arrange and present information in order to search for ideas. According to Fraenkel & Wallen (2000b, pp. 505-506) in qualitative study the data analysis is usually used to synthesise information that the researcher collected from various sources (e.g. interviews, observations, content analysis) into a logical description of what has observed.

Qualitative data analysis was 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 (Bailey 1997, p. 137). At first, it includes systemic organisation 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 began with transcription of the interviews. From data analysis researcher transcribed the entire interview in Bangla from a recorder. Researcher also observed the relevant issues related to the study and noted it down. After transcription was formulated, it was then given to three individuals who are 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. After that 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. Njoki stated (2004, pp. 50-51) that content analysis usually refers to analysing text. 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. During initial category coding, the researcher identified the coded major themes from each interview. The second stage involved identifying information units. Information

units were categorised into themes in relation to men with paraplegia in adjusting with sexuality from their perception. Finally analysis of interview data began by analysing text from the categorised data and coded themes. Researcher also analysed the key themes based on the literature.

3.11 Rigour

The research was conducted in a rigorous manner. All of the steps in the research process were supervised by an experienced supervisor. During the interview and analysis of data, researcher did not try to influence the process by his biases, values or own perspectives. During the interview the researcher always asked open-ended questions, no leading questions were asked and researcher did not interrupt the participants during answering the questions. Similarly during data analysis, researcher did not submit according to own perspectives. Data was 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 three 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.

Result and discussion are carried out all at once and presented together in this chapter. Bailey (1997, p. 197) states that “*The result and discussion were presented together in one section because this is common practice in reporting on qualitative studies*”. The objectives of the study were to find out the challenges men with paraplegia face during performing sexual activity and to identify how they adjust with those challenges to perform sexual activity in their personal lives.

Researcher determined general categories from completed data analysis and the themes that emerged were as follows:

- ◆ Understanding about sexuality. Under this category the coding is show in APPENDIX- VI. From this coding the emerging theme is-

Theme 4.1: Men with paraplegia are knowledgeable about sexuality.

- ◆ Challenges faced during sexual activity. Under this category the coding is illustrated in APPENDIX- VII. From this coding the emerging theme is-

Theme 4.2: Men with paraplegia face physical and psychological challenges during performing sexual activity due to their injury.

- ◆ Adjustment with different problems during sexual activity in personal lives. Under this category the coding is illustrated in APPENDIX- VIII. From this coding the emerging theme is-

Theme 4.3: Participants use different techniques to adjust with their challenges in performing sexual activity.

- ◆ Experiences of partner to adjust with sexual activity. Under this category the coding is shown in APPENDIX- IX. From this coding the emerging theme is-

Theme 4.4: Partners are practising different types of support to adjust with challenges to perform sexual activity.

- ◆ Support expected from their partner during sexual activity. Under this category the coding is shown in APPENDIX-X. From this coding the emerging theme is-

Theme 4.5: Men with paraplegia expect both physical and psychological support from their partner during sexual activity.

- ◆ Opinion about sexual life. Under this category the coding is illustrated in APPENDIX-XI. From this coding the emerging theme is-

Theme 4.6: Most of the participants could adjust with their challenges and felt satisfaction about their sexual life.

4.1 Men with paraplegia are knowledgeable about sexuality

Sexuality is a central aspect of human life. In human life, people define themselves and others from birth. Spinal cord injury has a great impact on sexuality in a person's life. Sexuality is very important for social relationships. Most people with a SCI have sufficient strength and ability to cope with the problems and the many frustrations imposed by disability.

All of the participants had received education about sexuality during the rehabilitation period at CRP, Savar. Men with paraplegia demonstrated knowledge about sexuality. However they felt much discomfort and shyness to talk about that personal matter with researcher. Most of the men with paraplegia expressed that sexuality meant having physical contact, sexual intercourse and to stay with their wife.

One of the participants stated

“Sexuality is interacting with my wife. There may be kissing, hugging, stay close together and touching each together. Sexuality is living together as husband and wife”.

Another participant differently stated

“Sexuality is an interacting relationship with my wife, hugging, kissing, touching her sexual organs to increase excitation to an optimum level. Sexuality is living together and enjoying this”.

According to the Illustrated Oxford Dictionary (2003, p. 758), *“Sexuality is the feelings and activities that is connected of relating to sex and relations between partners”.*

Men with paraplegia are unable to move their lower limbs properly. One participant mentioned that *“Sexuality is very important for all disabled. It is essential to be interacting with each other, that is important for sexual satisfaction. Disabled people are not able to do those things like person without disabilities. For this reason, disabled people think of some alternative ways. That is called sexuality”.*

Sexuality is more than physical intimacy between two people in bed. People with a SCI have changed sensations or loss of feelings. These people have found much pleasure by discovering their partner’s body in a new way (Hammond et al. 1989, p. 217).

Sexuality is a very important and essential matter for human life. It is important for people with and without disabilities. It is also important for social relationships, to maintain relationships, to wield power and communicate with others. Spinal cord injury does not alter this. Person with a SCI has the same sexual desire for sexual expression. SCI affects a person’s physical capacity to perform sexual acts.

4.2 Men with paraplegia face physical and psychological challenges during performing sexual activity due to their injury

Spinal cord injury is one of the most interrupting life events for injured people. SCI affects sexuality because after the injury the person’s physical capacity has changed. When men with paraplegia engage in sexual activity with their partner then they face different challenges.

Researcher found all participants had experience in sexual activity with their partner. The participants engaged in sexual intercourse and faced challenges during sexual

activity with their partner. Those challenges create different types of problems in their lives.

SCI creates different types of physical, social, sexual and emotional problems in a person's life. There are many physical and psychosocial factors responsible for creating problems in a person's sexual life. Person with a SCI life has great on sexual performance of those factors.

Physical factors:

Bowel and bladder incontinence:

Bowel and bladder control is very important for person with a SCI. Bowel and bladder incontinence may create big problems during sexual activities. Bowel and bladder management is vital during sexual activities. Most of the participants mentioned that it is great challenge of performing sexual activity.

One of participant mentioned

“I have no sensation for managing bowel and bladder. So micturation may occur during sexual activity. This is a great problem and I feel scared about this problem”.

Somers (1992, p. 275) discuss that bowel and bladder incontinence can create problems during sexual intercourse. Spontaneous sexual intercourse can be hampered due to problems controlling bowel and bladder.

Risk of pressure sore:

Pressure sore is one of the greatest complications for person with a SCI. Many people with a SCI have pressure sores that may affect their personal lives. People with a SCI are very anxious about pressure sores. Most of the participant said that risk of pressure sore was one of the big problems in their sexual lives. They are always scared of the risk of creating pressure sores.

One of the participants mentioned

“People who are disabled have to face a lot of problems in their lives. They are not able to do many things like a person without disability. Risk of pressure sores is one of the biggest problems in sexual activity”.

Another participant said

“The first time I engaged in sexual relationship with my partner, I was not able to control my proper position. I developed pressure sores in different places on my body”.

Pressure sores are a common problem during sexual intercourse. Partner needs to avoid any unnecessarily rough or harsh handling during sex. They also need to remember that prolonged pressure can create a pressure sore on any body part during sexual activity (Fallon 1978, p. 96).

Pressure sore is a common complication. It may create difficulties to maintain positioning and mobility (McKenna 2003, p. 543). Men with paraplegia are very anxious due to risk of pressure sore during sexual intercourse. A person with a SCI's sensation is partially or fully damaged after the injury. If a person with a SCI is engaging in sexual relationships with their partner, then they are scared that they may develop pressure sores.

Loss of movement:

People with a SCI need different types of movement when performing sexual activities. After the injury people are unable to move properly. Most of the participants said that loss of movement is a big challenge for them during sexual activity.

One of the participants said

“As a disabled person proper movement is very difficult for me. I was unable to move like a person without disability”.

Kreuter et al. (1998, p. 252) stated that for a person with a SCI, the implications are mostly physical which affect sexuality, but having a physical disability will not alter the men's need for intimacy and affection.

Loss of sensation:

People with a SCI have altered body sensation after the injury. Those people are very worried about their loss of sensation. That may cause frustration and decrease the quality of sexual activity. Most of the participants said that they are not able to enjoy sexual intercourse properly due to loss of sensation.

One of the participants stated

“I have no sensation. So I do not feel any interest to interact with my partner. However I try to satisfy according to my partner’s desire. For this reason many problems arise”.

Men with paraplegia have some sexual impairment. Sex and SCI is a complex issue due to overall physical paralysis and limitation of the body parts movement. A person with a SCI has great experiences of sensory loss. It is a big challenge for them to ensure physical excitement (Spinal cord injured male n.d.).

Pain:

Pain in the lower back and knees is another big challenge for people with a SCI. Three of the participants complained that they faced this challenge during sexual intercourse.

One of the participants stated

“I face difficulty to position independently. I have to depend on my partner. When she wants sexual interaction with me that time I feel afraid of getting pain in lower back and knee”.

Pain is a common phenomenon. It is responsible for creating dissatisfaction during sexual activities (Atkins 2002, p. 972). Pain causes limitations or further decreases interest in sex or sexual performance (Klein & Merritt 2008).

Pain is an uncomfortable sensation for every person. People with a SCI have experienced pain at some point after injury. Pain can occur anytime after injury. For the survivors of SCI, pain is unremitting due to hypersensitivity in some part of the body. Pain in the lower back and knees may arise during sexual intercourse for men with paraplegia. Sometimes pain interferes badly in men with paraplegia’s lives. Therefore it may cause a negative impact in their sexual lives.

Psychosocial factors:

Men with paraplegia face different types of psychosocial challenges during sexual activity. Sometimes they need to depend on their partner during sexual intercourse. Men feel their role has changed in their relationship.

One of the participants mentioned

“As a social barrier there is a problem with marrying a person with disabilities within society, people think that they can not marry”.

A recent review of available research shows that sex acts involving people with disabilities are viewed more negatively than when these same behaviours are considered in the context of non-disabled people (Giulio 2003).

Most of the participants feel very afraid about sexual relationships with their partner. They have poor self-esteem about this activity. One of the participants said *“When I want to have sexual intercourse with my partner that time I feel fear which may increase my different problems”.*

People with a disability can also internalise negative attitudes and beliefs around sexuality and disability. In some cases, the presumption of asexuality can become a self-fulfilling prophecy, leading people with disabilities to retreat from intimacy and sexuality (Giulio 2003).

After the injury a person with a SCI life style has changed. Social consequences add problems in a person’s life. People with a SCI are very depressed after the injury. The injured person uses a wheelchair or orthoses and other assistive devices. People with a SCI are viewed by others as sexless, devoid of sexual urges and undeserving of sexual expression. These types of societal attitudes can severely limit opportunity for sexual expression.

4.3 Participants use different techniques to adjust with their challenges in performing sexual activity

After a traumatic injury a person with a SCI faces different problems in their lives. Problems are due to physical and psychosocial changes. This causes different internal and external barriers in performing sexual activity. People with a SCI need to adjust with those barriers. Men with paraplegia face challenges during sexual activity. People with a SCI try to adjust with challenges by discussion, maintaining proper positioning and gathering knowledge from different sources.

Participants spoke about adjust with challenges by using different techniques to perform sexual activity. Most of the participants mentioned that they had discussed this issue with doctors, therapists, partner and peer with disability. They tried to

follow health professionals' instruction in their sexual life. Participants also said that they were finding out alternative ways and maintain proper positioning during sexual activity.

One of the participants said

“I discussed with doctors, therapists and peer with disability to adjust to challenges and followed their instructions. I also discussed with my partner before and after marriage. My partner helps me to move and maintain appropriate position. If we face challenges then we find out alternative way for sexual relationship”.

People with a SCI like spontaneity and the freedom to explore with their partner. Sexual activities require some planning after the injury. At this time patients need to take time to explore themselves in front of their partner. Men with paraplegia can take suggestion from social worker, psychologist and other rehab team members at this time (Hammond et al. 1989, p. 230).

Another participant reported

“I read some books about sexuality. I imagine some dream that is giving me enjoyment. My partner tries to help me to maintain a comfortable position”.

American National Spinal Cord Injury Association reported on services needed and services offered in a rehabilitation program. The study suggested different programs for people with a SCI. The programs included a doctor being open and available for consultation, education about alternative ways and maintaining positioning, combination of written materials, videos and individual counseling and consultation, access to other people with a SCI who have more sexual experience (Jurisic 1993, pp. 18-20).

One of the participants mentioned

“I am trying to do such type of work that is beneficiary for my partner. I try to overcome my problems. If I get a new idea then I will use different techniques in the future”.

People with a SCI know about different alternative ways to engage in sexual intercourse. Patients tried to implement those techniques when face a problem. It may

also be appropriate to encourage partner to take a more active role in sexual intercourse (McKenna 2003, p. 545).

4.4 Partners are practising different types of support to adjust with challenges to perform sexual activity

After the injury people with a SCI's normal sexual function is interrupted. Therefore patients need to adjust to changes in their sexual life. Sexual adjustment is very important for both the patient and his partner. Partners used different technique for adjust with sexual activity. Most of the participants mentioned that their partner is practising different techniques, such as maintaining suitable position, ensuring appropriate environment and helping find solutions to other sexual problems, in order to have a fulfilling sexual life.

One of the participants said

“My partner always helps me in all activities for sexual intercourse. She helps me to maintain appropriate position, is careful about pain, ensures a comfortable environment, is conscious of blister formation and helps me to avoid pressure sores. She always reminds me to complete bowel and micturation activities before sexual intercourse. My partner is always willing to engage in sexual activity”.

Men with paraplegia need to readjust with sexuality after injury. A couple tries to take the time to explore new sexual responses. Partner tries to use different techniques of positioning, comfortable environment and to learn new ways to enjoy sexual intercourse. Partner also concentrates on new ways so that they can sexually pleasing their partner (Spinal cord injured male n.d.).

Another participant mentioned

“My partner helps me to change position during sexual activity. She is conscious about bowel and bladder management. My partner tries to give satisfaction as much as possible”.

Men with paraplegia need to maintain different positions for safety and comfort during sex. It is useful if a person with a SCI can have a bowel and bladder motion before sexual activity (Moving forward: the guide to living with spinal cord injury 1995).

Sexual activity not only depends on the person with a SCI but also their partner. Men with paraplegia face different physical and psychological challenges during their sexual life. Their partners need to adjust with those challenges. Partners are using different techniques to adjust with those challenges. Partners are helping in changing position, being aware of different health related problems and finding suitable ways to perform sexual activity. Men with paraplegia are not able to achieve satisfaction in their sexual lives without their partner's help. If men with paraplegia's partners are able to adjust with those challenges, it is beneficial for their own adjustment.

4.5 Men with paraplegia expect both physical and psychological support from their partner during sexual activity

A person with a SCI's physical capacity, functional performance and motor abilities are changed following injury. They need support to improve in those areas from their partner. Sexuality is an important issue for men with paraplegia. In this area patient needs support from their partner. Most of the participants have different expectations of their partner in sexual activity. The expectations included to take care, consider the problems, help to get satisfaction, give enjoyment and find out the suitable position during sexual activity.

One of the participants mentioned

"I expect that my partner helps more and takes care during performing sex. My partner also considers all problems during sexual activity. She helps to fulfil satisfaction and give pleasure. My partner does not see me as a disabled person".

Another participant said

"I expect that my partner will be co-operative during sexual intercourse and is always aware about problems".

Every person with a disability needs support more or less in the day-to-day activities including sexual activities. Everybody requires preparation and co-operation before having sex with another person (Kreuter et al. 1998, p. 254).

People with a SCI are not able to perform independently sexual activities due to their physical capability. They require support in all aspect during sex. Their partner can help them by providing different types of supports. Partner's cooperativeness can help to lead satisfied sexual lives for people with a SCI.

Two participants reported that their partner helps to find suitable positions for sexual intercourse. One of the participants said *"My partner always considers which position is suitable for me. She also thinks in which position will fulfil my satisfaction. She will continue to consider these things in future"*.

People with SCI need to know how to maintain different positions to be comfort able and safe during sex (Moving forward: the guide to living with spinal cord injury 1995).

A person requires both physical and emotional strength to perform sexual activity. Men with paraplegia need both physical and psychological supports from their partner. Partners are helping them different aspects of their sexual lives. That is more comfortable for them in their sexual activities. Sexuality and sexual function is a very important component to adjust to after SCI. It is also necessary for sustaining a family life and social relationship.

4.6 Most of the participants could adjust with their challenges and felt satisfaction about their sexual life

Sexual function depends on the level of the injury. A person with a SCI's satisfaction varies from person to person. Most of the participants reported being satisfied with their sexual life, but two participants are not satisfied with their sexual life.

One of the participants mentioned

"I am satisfied with my sexual life. I am getting satisfaction from my partner that is enough for me. I have no further need. If I wanted anything more than problems will arise. I do not want to face anymore any problems".

Another participant said

“I am satisfied with my sexual life. However I see that my partner helps me in all kinds of ways. I have seen many people who face greater problems than me. For this reason I am satisfied”.

People with a SCI are able to fulfil psychological, social and physical issues in their sexual lives. This fulfilment can help those continuing satisfied sexual lives with their partner (Atkins 2002, pp. 971-972). If a person with a SCI can adjust with different sexual problems that will ensure him a satisfactory sexual life. Sexual adjustment is essential for their lives.

Other participants stated

“I am not satisfied with my sexual life. My condition is worse than other patients. I have no full sensation. That’s why I do not get any pleasure. My partner is a normal person so she expects satisfaction and a pleasurable sexual life from me. However she is unable to experience pleasure. I am not able to maintain proper position and movement”.

A report described that person with a SCI has strengthened their sexual satisfaction with adjustment after post-injury marriage (Ide & Fugl-Meyer 2001, pp. 390-91).

Men with complete paraplegia are not able to adjust fully with their sexual lives. This creates dissatisfaction on their lives. Sometimes patients expected more according to their level of injury. Their sexual education is not sufficient for them in their sexual life. This causes dissatisfaction in their sexual lives. The researcher also found that post-injured married SCI man are more capable to adjust with their sexual challenges rather than pre-injures married SCI man. All of the post-injured married SCI men reported satisfaction with their sexual lives in comparison to those who married prior to the injury.

There are some limitations that should be kept in mind during conducting the study. The researcher always tried to consider these limitations. The limitations are given below:

- ❖ This study is qualitative study. In this study purposive sampling was used to select the participants. A small sample size is preferred when in-depth information is required. The findings of this study cannot be generalised to all men with paraplegia. Because the sample size was small.
- ❖ The findings of the study are not applicable for the female with SCI. Because females with SCI were not participants of this study. Including female with SCI in the study might provide more interesting information.
- ❖ Interview was conducted in Bangla. However the study is presented in English. So had to translate interview information from Bengali to English. Sometimes it may difficult to discover actual meaning of some information from the data translation. But researcher tried heart and soul to give the actual information of the data in the study.
- ❖ Partners were not included in this study. Partners may not have felt comfortable to share their experiences due to cultural context with male researcher. Experienced female data collectors were unavailable to be involved in this study.
- ❖ There were limited resources and information available about sexuality because it is a new study within a Bangladeshi context.

Recommendations for Occupational Therapists in Bangladesh:

Occupational Therapists (OT) should adopt a broader role and holistic treatment techniques on the fact of sexuality for people with SCI. OT need to up date their knowledge in this area. OT should involve patients and their partners in sexual counseling and motivate them to perform sexual activity. OT needs to concentrate more on this issue during the rehabilitation period.

Recommendations for further research:

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

- ♣ A survey to discover a person with a SCI and their partners' satisfaction about their sexual lives following spinal cord injury.
- ♣ Experiences of men with tetraplegia to adjust to their sexuality following spinal cord injury.
- ♣ Find out the value of qualified Occupational Therapists and Occupational Therapy students' practising sexual counselling with their clients and partner.
- ♣ Researcher also recommends that OT need to study sexuality in different areas like as stroke and head injury. To discover the current status of sexuality in stroke patients.

Further research should be conducted with a large numbers of participants on this study design. If researcher conducts the study with large samples then it will be easy to generalise the result.

All men with SCI have received education about sexual activities from CRP to complete their rehabilitation program. They are trying to lead comfortable and active sexual lives with their partner. Some of the physical changes and other challenges facilitate on their sexual lives. This may have great impact on their sexual adjustment. All of the men with paraplegia share their ideas about their sexual lives. Most of the men are satisfied about their sexual lives. However some men with paraplegia are not getting satisfaction in performing sexual activity.

A person with a SCI is characterised by the presence of different health related problems. The findings of the study indicate that participants had to adjust with ongoing physical factors such as bowel and bladder incontinence, loss of movement, loss of sensation, pain in the lower back and knees and risk of pressure sores as well as psychological factors. The person with a SCI has no choice but to be careful in regards to proper positioning and needs partner's support during performing sexual activities. Usually partner always helps them during performing sexual activity. Men with paraplegia and their partner find different alternative ways, suitable positions and comfortable environments that is suitable for them to engage in sexual intercourse. Men with paraplegia need their partner's support to adjust to express their sexuality in their personal lives.

Spinal cord injury affects an individual and their family physically, psychologically, socially and economically. However it should be considered that it is necessary to provide more information during the rehabilitation period. The main aim is to helping person with a SCI to adapt to the new conditions and so that they will be able to express their sexual expression in a new way. Skilled Occupational Therapists can help them in different ways to adapt their new situation in their sexual lives. Occupational therapists will listen and take actions which fulfill their professionals' role. Researcher hopes, if therapists concentrate on this issue properly it may improve quality of life for people with a SCI.

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APPENDIX- I (a)

সম্মতিপত্র

এই গবেষণা অকুপেশনাল থেরাপি বিভাগের অধ্যয়নের একটি অংশ এবং গবেষকের নাম মীর হাসান শাকিল মাহমুদ। তিনি বাংলাদেশ হেল্থ প্রফেশনস ইনস্টিটিউটের বি. এস. সি. (অনার্স) ইন অকুপেশনাল থেরাপি বিভাগের ৪র্থ বর্ষে অধ্যয়নরত একজন ছাত্র এবং তার গবেষণার বিষয় “মেরু-রঞ্জুতে আঘাত পরবর্তী প্যারাপেণ্ডিক পুরস্কদের শারীরিক সম্পর্ক/যৌনতার সঙ্গে খাপ খাওয়ানোর/অভিযোজনের অভিজ্ঞতা”।

এই গবেষণার আমি একজন অংশগ্রহণকারী এবং আমি এই গবেষণার উদ্দেশ্য পরিষ্কার ভাবে জানতে পেরেছি। আমি যে কোন সময় এবং গবেষণার যে কোন পর্যায়ে আমার অংশ গ্রহণ প্রত্যাহার করতে পারি। এই জন্য আমি কারো কাছে জবাব দিতে বাধ্য থাকব না। আমি অবগত হয়েছি যে, এই গবেষণার অংশ গ্রহণ করার ফলে বর্তমানে এবং ভবিষ্যতে আমার চিকিৎসা গ্রহণের উপর কোন প্রকার প্রভাব পরবে না।

এই গবেষণার সাক্ষাৎকারের সকল তথ্য যেগুলো গবেষণার কাজে ব্যবহৃত হবে, সে গুলো সম্পূর্ণভাবে গোপনীয় থাকবে। শুধুমাত্র গবেষক এ তথ্য গুলোর প্রবেশাধিকার পাবে। আমার নাম, পরিচয় ছাপা হবে না।

আমি গবেষণার পদ্ধতি এবং জটিলতা অথবা সুফলের ব্যাপারে বা গবেষণা সংক্রান্ত যে কোন প্রশ্নের উত্তরদানের জন্য এই গবেষণার তত্ত্বাবধায়কের সহিত আলোচনা করতে পারব। আমি উপরোক্ত সকল তথ্য গুলো সম্পর্কে জানি এবং আমি এই গবেষণায় অংশগ্রহণে সম্মতি জ্ঞাপন করছি।

অংশগ্রহণকারী স্বাক্ষর/টিপসই:	তারিখ:
গবেষকের স্বাক্ষর:	তারিখ:
স্বাক্ষীর স্বাক্ষর/টিপসই:	তারিখ:

APPENDIX- I (b)

Consent Form*

This research is part of Occupational Therapy course and the name of the researcher is Mir Hasan Shakil Mahmud. He is a student of Bangladesh Health Professions Institute (BHPI) in B. Sc. (Honours) in occupational Therapy in 4th year. The study was entitled as **“Experiences of men with paraplegia to adjust to their sexuality following spinal cord injury”**.

In this study I am a participant and I have been clearly informed about the purpose of the study. I have the right to refuse in taking part at any time and at any stage of the study. I will not be bound to answer to anybody. I understand that there will be no impact receiving treatment at present or in the future by participating in this study.

I am also informed that, all the information collected from the interview that is used in the study would be kept safe and maintain confidentiality. Only the researcher will be eligible to access in the information for his publication of the research result. My name and address will not published anywhere in this study.

I can consult with the researcher and the research supervisor about the research process or get answers to any questions regarding the research project. I have been informed about the above-mentioned information and I am willing to participate in the study with consent.

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

* Translated copy

APPENDIX- II (a)

সাক্ষাৎকারের প্রশ্ন নির্দেশিকা

১. দয়াকরে বলবেন কি, শারীরিক সম্পর্ক/যৌনতা বলতে আপনি কি বুঝেন?
২. দয়াকরে বলবেন কি, শারীরিক সম্পর্ক স্থাপনের সময় আপনি কি কি বাঁধার সম্মুখীন হয়েছেন?
৩. আপনার ব্যক্তিগত জীবনে কিভাবে আপনি এসব সমস্যার সঙ্গে নিজেকে খাপ খাইয়েছেন/অভিযোজিত করেছেন?
৪. দয়াকরে বলবেন কি, শারীরিক সম্পর্ক সম্পাদনে আপনার সঙ্গী কিভাবে আপনার সঙ্গে খাপ খাওয়ানোর/অভিযোজনের চেষ্টা করছেন?
৫. আপনি শারীরিক সম্পর্ক স্থাপনে আপনার সঙ্গীনির কাছ থেকে কি ধরনের সাহায্য আশা করেন?
৬. আপনি কি আপনার যৌন জীবন নিয়ে সন্তুষ্ট? হ্যাঁ/না। দয়াকরে বিস্তারিত আলোচনা করুন।

APPENDIX- II (b)

Interview Questionnaire*

1. Would you please explain, what do you mean by sexuality?
2. Would you please explain, what are the challenges you face during sexual activity?
3. How do you adjust with those problems in your personal life?
4. Would you please explain how your partner is adjusting to sexual activity with you?
5. What types of support do you expect from your partner?
6. Are you satisfied with your sexual life? Yes/No. Please explain your opinion.

* Translated copy

APPENDIX- III

Date: 10th August, 2008.

To
The Course Coordinator
Dept. of Occupational Therapy
BHPI.

Subject: **Prayer for seeking to conduct the research project.**

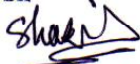
Sir,

With due respect, I am seeking permission to conduct the research project as a part of my 4th year course module. My research title is "Experiences of male paraplegic people to adjust with sexuality in their personal life". The aim of the study is to explore experiences of male paraplegic people to adjust with sexuality in their personal 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 pray and hope that your honor would be kind enough to grant me the permission of conducting the research and will help me to conduct a successful study as a part of my course.

I remain


Sir



10.08.08

Mir Hasan Shakil Mahmud
4th year, B. Sc. (Honours) in Occupational Therapy
BHPI.

Attachment: Proposal of research.

Signature and comments of the Supervisor	Signature and comments of the Course Coordinator
<p>It may allow him to conduct this study as a part of completion of his B.Sc(Hons.) course in Occupational Therapy.</p> <p>- Nazmun Nahar 10.08.08</p> <p>Nazmun Nahar B. Sc. (Honours) in Occupational Therapy Lecturer and Research supervisor Dept. of Occupational Therapy, BHPI, CRP, Savar, Dhaka-1343.</p>	<p>Permission is given. Concern authorities are requested to cooperate him.</p> <p>-  10.08.2008</p> <p>Mohammad Mosayed Ullah B. Sc. (Honours) in Occupational Therapy Course Coordinator and Lecturer, Dept. of Occupational Therapy BHPI, CRP, Savar, Dhaka- 1343.</p>

APPENDIX- IV

Checklist of participants

Information about participants at a glance:

Participant's Information	P1	P2	P3	P4	P5	P6
Age	42	30	33	28	37	40
Sex	M	M	M	M	M	M
SCI (Type)	T/P	T/P	T/P	T/P	T/P	T/P
Neurological level	T ₁₂	L ₁	L ₁	L ₁	L ₁	T ₁₀
Level on ASIA impairment scale	D	D	C	A	A	A
Aid use	Elbow crutch	Elbow crutch	W/C	W/C	W/C	W/C
Do marriage	After injury	After injury	After injury	Before injury	Before injury	After injury
Education	Graduate	B. Com	Graduate	HSC	Graduate	Illiterate
Occupation	Job	Job	Job	Electronic maker	Job	Job

(N.B.; M= Male, T/P= Traumatic Paraplegia, T= Thoracic, L= Lumber, W/C= Wheelchair)

APPENDIX- V

APPENDIX- VI

Category: Understanding about sexuality.

Coding	P1	P2	P3	P4	P5	P6
Interaction sexual relationship with partner	✓	✓	✓	✓	✓	✓
Kissing	✓		✓	✓	✓	
Alternative ways of sexual relations	✓					
Touch different sexual organs		✓			✓	
To increase physical excitation		✓			✓	
Living together of husband and wife			✓	✓	✓	✓
Hugging			✓	✓	✓	
Stay close together			✓	✓		
Touch each other				✓		✓
Helping each other						✓

APPENDIX- VII

Category: Challenges faced during sexual activity.

Coding	P1	P2	P3	P4	P5	P6
Bowel and bladder incontinence	✓		✓	✓	✓	
Risk of pressure sore	✓	✓		✓	✓	
Pain in the lower back and knees	✓			✓	✓	
Loss of movement	✓		✓	✓	✓	
Loss of sensation	✓			✓	✓	✓
Positioning problem	✓	✓	✓	✓		
Convulsions problem						✓
Social barrier	✓	✓		✓		
Fear about sexual relationship			✓	✓	✓	✓
Psychological barrier	✓		✓		✓	
Partner satisfaction			✓		✓	
No practical knowledge about sexuality			✓			✓

APPENDIX- VIII

Category: Adjustment with different problems during sexual activity in personal lives.

Coding	P1	P2	P3	P4	P5	P6
Discuss with doctors	✓	✓	✓	✓	✓	✓
Follow advice of therapists	✓	✓	✓	✓		✓
Discuss with wife	✓	✓	✓	✓		✓
Talking peer with disability	✓	✓		✓	✓	✓
Help to change movement during sexual activity	✓				✓	
Find out alternative way	✓	✓	✓	✓		✓
Maintain appropriate position	✓	✓		✓		
Reading books		✓	✓		✓	
Watching video clips	✓	✓				
Practice new idea			✓		✓	

APPENDIX- IX

Category: Experiences of partner to adjust with sexual activity.

Coding	P1	P2	P3	P4	P5	P6
Maintain suitable position	✓	✓	✓		✓	
Help in all aspect of sexual problem	✓	✓	✓	✓		✓
Careful about pain	✓		✓			
Not creating pressure sore	✓	✓	✓			
Make sure suitable environment during sexual activity		✓	✓			
Avoid social barrier		✓				
Help to changing position		✓		✓	✓	
Bowel and bladder management			✓		✓	
Inspired about sexual activity			✓			✓
Avoid blister formation			✓			
Careful about health related problems			✓	✓		✓
Ensure sexual satisfaction				✓	✓	
Discuss with other problems						✓

APPENDIX- X

Category: Support expected from their partner during sexual activity.

Coding	P1	P2	P3	P4	P5	P6
Find suitable position	✓		✓			
Help to get satisfaction	✓	✓		✓	✓	
Give more enjoyment during sexual activity	✓	✓		✓	✓	
Consider all problems during sexual activity in future life	✓		✓	✓	✓	✓
Always aware about health and positioning		✓				✓
Take care during sexual activity		✓	✓	✓	✓	✓
Help to avoid all problems		✓		✓		
Not thinking of partner as a disabled person				✓		✓
Show good behaviour all the time					✓	
Cooperative when felt sexual excitement					✓	

APPENDIX- XI

Category: Opinion about sexual life.

Coding	P1	P2	P3	P4	P5	P6
Satisfied about sexual life	✓	✓	✓			✓
Dissatisfied about sexual life				✓	✓	
Have a child for family life	✓					
Live a better conjugal life as a normal person	✓					✓
Played great role in family	✓	✓				
No problem faced in his sexual life at this stage		✓				✓
No extra demand needed for sexual life			✓			
That is enough for life			✓			✓
Unable to give satisfaction to partner				✓	✓	
Partner not interested to stay with me				✓		
Unable to move properly					✓	
Unable to feel proper excitement					✓	
Unable to overcome those problems properly					✓	