

**What are the Demographic Factors of the Caregiver of the Person with
Spinal Cord Injury in CRP**

Bangladesh

By

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STATEMENT OF AUTHORSHIP

Except where reference is made in the text of the thesis, this thesis contains no material published elsewhere or extracted in whole or in part from a thesis presented by me for any other degree or diploma or seminar.

No others person's work has been used without due acknowledgement in the main text of the thesis.

This thesis has not been submitted for the award of any other degree or diploma in any other tertiary institution.

The ethical issue of the study has been strictly considered and protected. In case of dissemination of the findings of this project for future publication, it will be duly acknowledged as undergraduate thesis.

Signature: _____ Date: _____

(Mst. Sabrina Sarwar)

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Dedication

.....The research is dedicated to my parents who are making everything worthwhile.

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KEY ABBREVIATIONS

ADLs: Activities of Daily Living.

BHPI: Bangladesh Health Professions Institute.

CRP: Centre for the Rehabilitation of the Paralyzed.

SCI: Spinal Cord Injury.

WHO: World Health Organization.

ABSTRACT

According to World Health Organization (WHO) data, it is estimated that approximately 650 million people all round the world are living with a disability (WHO 2010) and at least 20% of the people are disabled in some developing countries. The UNESCAP suggest 400 million people with disabilities lives in Asia. According to Bangladesh Bureau of statistic (2010-2011), Bangladesh disability rate is very high and it is near about 9.07% - 9.63% among those people who are living in rural areas and 7.49% living in urban areas.

Aim: To identify current demographic factors of caregivers of SCI patients in CRP.

Design: Cross sectional study design.

Sample size: Total 79 individuals who met the inclusion criteria for this study.

Setting: Spinal cord injury unit of CRP.

Results:

In this research gender of the male 8.86% & female 96.20%, married participants were 3.710%, most of the participants were age range 35 to 44 years were 36.71%, the relationship of the most participants were wives of the patient were 53.16%, most of the participants were muslims 91.14%. The various family members were 5 to 7 members of participants were 49.37%, 41.77% of the caregivers were not educated. Income level of the most participants were up to 3,000 taka 45.57%, most of the patient were tetraplegic 59.49% & complete level of injury 64.56%.

Conclusion:

The study also had been shown that most of the female caregivers provide care giving to the male patient but there were no male caregivers for female patients. So, it is important to encourage the male caregivers to participant in care giving activities of female patients and recommend that special training for caregivers of spinal cord injuries patients.

1.1. Background:

Spinal cord injury is a disabling condition and it has been occurring since antiquely in the history of the human creature. SCI is one of the most common causes that make people disabled. In Bangladesh many people are being disabled due to SCI every year. Currently this condition has become a major health problem. When a person is injured with SCI, it affects all aspects of the person's life. SCI is a life altering experience for both of the patients and the caregivers. Caregivers assist patients in managing medications, therapy, and medical emergencies; provide supervision, emotional support, assist in personal care, mobility and other basic daily living activities. In Bangladesh it is seen that the close relatives along with family members are mostly engaged in care giving for a person with SCI. The disabling conditions of patients impact on usual daily living activities of the caregivers. SCI patients have longer life expectations than other degenerative conditions. As a result caregivers for person with SCI have to engage themselves for a long time in care giving for the patient. Many studies found that the primary caregivers and/ or spouses of SCI survivors may experience various problems due to this disorder. Research in the literature regarding the quality of lives of primary caregivers of SCI survivors is relatively limited. SCI significantly interferes with the care givers quality of life not depends on severity of injury (Unalan et al., 2001, pp. 318-322). A similar study found that caregiver sex, child age at injury and child mental health were related to caregiver outcomes. Caregiver mental health and education and child social relationships predicted child outcomes. Neither injury level nor injury severity was related to caregivers or child outcomes (Kelly et al., 2011, pp. 200-205). It depends on caregiver's demographic factor such as sex, caregiver's education etc. Therefore, more research is needed to establish caregiver's demographic factors in a Bangladeshi context.

1.2. Literature review of the study:

1.2.1. Spinal cord Injury:

Spinal cord injury usually occurs after a sudden, traumatic damage to the spine. This injury or damage results in fracture, dislocation of vertebrae, intervertebral discs which in turn rupture the spinal cord partially or completely. Axons are cut off or damaged beyond repair and neural cell membranes are broken. Blood vessels may rupture and cause heavy bleeding in the central grey matter, which can spread to others areas of the spinal cord over the next few hours.

Ekman (2002, P. 132) described that common dysfunction of the spinal segments occurs as a result of trauma to the spinal cord.

According to Fitz Geral (1995, P. 29) Spinal Cord Injury means “lack of sensory and motor function in the lowest sacral segment.”

“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).

When one sustains a SCI, there are some features found below the specific segmental level of Injury immediately after a complete SCI. These are, movements and any kinds of sensation are lost below the level of injury and limbs become flaccid and tendon reflexes are diminished, bowel and bladder control are also lost.

1.2.2. Cause of SCI:

Spinal cord injury occurs as a result of both traumatic and non-traumatic incidences. There are many causes of spinal cord injury in Bangladesh. The most common causes of spinal cord injury in Bangladesh are fall from a height, road traffic accident; fall down while carrying heavy load on head, fall of heavy object on back, bull attack, bullet injury or gunshot injury, physical attack, disease process, diving in shallow water and others (Ekman, 2002, p. 284-285).

SCI results from an accident that breaks or severely damages the spinal cord and its segments in the neck or back. It was found that the cervical cord is most commonly affected. In the western world, automobile accidents are the most common causes of SCI. More than half of SCI patients are within 15-30 years old (FitzGerald, 1995, p. 127). In CRP the most common cause of traumatic lesions was a fall from a height followed by falling when carrying a heavy weight on the head and road traffic accidents. Most of the patients were between 20-40 years old and the overall age group ranged from 10-70 years. The male: female ratio was 7.5: 1.0. Among the traumatic spinal cord lesions, 60% were paraplegics and 40% tetraplegics. Among the non-traumatic spinal cord lesions cases 84% were paraplegics and 16% tetraplegics. The leading causes of death resulted from respiratory complications and these deaths occurred in the very early period of admission (Fazlul Hoque et al. 1999, p. 858).

1.2.3. Types of Spinal cord Injury:

There are two types of spinal cord Injury

- ❖ Tetraplegia
- ❖ Paraplegia

Tetraplegia:

Quadriplegia, also known as tetraplegia, is paralysis caused by illness or injury to a human that results in the partial or total loss of use of all their limbs and torso. The loss is usually sensory and motor, which means both sensation and control are lost. This means the arms, hands, trunk, legs and pelvic organs are all affected by the spinal cord injury.

Paraplegia:

When the level of injury occurs below the first thoracic spinal nerve. The degree at which the person is paralyzed can vary from the impairment of leg movement, to complete paralysis of the legs and abdomen up to the nipple line. This paralysis affects all or part of the trunk, legs and pelvic organs.

1.2.4. SCI can be incomplete and complete:

Incomplete:

The term incomplete injury is used only when there is partial preservation of sensory and motor function below the neurological level and including the lower sacral segment.

Complete:

The term complete injury refers to an absence of sensory and motor function in the lowest sacral segment (Hollar, as cited in Trombly, 1995, P. 796).

The classification of SCI depends on the neurological examination. When one has complete SCI there will be no sensory or motor functions below the level of injury and abnormal autonomic function (Feinberg and Minar, 2012).

1.3. Spinal cord injury in Bangladesh:

Bangladesh has achieved a tremendous gain in health care provision although a lot of demands with inadequate resources are the real picture of the health sector (Osman 2010). Bangladesh is a young country and its economic and medical facilities are continually developing day by day. However, public health issues has become confined with maternal and child health issue in regarding new initiatives. The facilities in other sector are not yet wide spread all over country due to combination of negative forces for example illiteracy, low socio-economic conditions, poor infrastructure, and ignorance (Haque, Grangeon & Reed 1999). Spinal cord injuries remain neglected, as there is not enough data and service for person with SCI. As a result, SCI have become a major public health problem in Bangladesh. However, in every aspect of public health issues, needs a careful concern. The key health indicator is life expectancy (Osman 2010).

A recent study found very low life expectancy of spinal cord injury in different periods. The study found that the life expectancy of person with SCI is 10 to 12 time lower than life expectancy of general population (Razzak et al. 2011). The major causes of death at home indicates negative social acceptance, lack of proper re-integration in community, less attention or care from the family member and poor quality of life following discharge

from the hospital and the study specifies inadequate acute management is a major cause of overall mortality (Razzak et al. 2011).

Likewise, another study also revealed that in general, inadequate services, poverty, negative attitudes of society towards person with SCI, inequitable laws, inaccessible built environment and transport systems are the main causes of poor integration of person with SCI into community life (Momin 2003; Lysack, Komanecky, Kabel, Cross & Neufeld 2007). This data shows that people with SCI have to fight with the rights of having access to the mainstream treatment facility across the country. The rehabilitation program will be unfulfilled without raising awareness among the family and community people about the ability of the person with SCI. Therefore, prevention, proper acute medical treatment and rehabilitation only can increase survival expectation of persons with SCI. Even though Bangladesh is a developing country, accidents are more prominent due to lack of structural development, poor medical facility and lack of awareness among the people about safety precautions during performing any risky job (Rathore 2011). Therefore, the situation of Bangladesh is even worse as a developing country. A study aimed to investigate life expectancy of people with SCI followed by 10 years revealed that only 16.4% of study population survived for 10 years which was much lower than developed countries like Finland (97.9%), Australia (86%), Canada (92%), UK (85%), USA (80.7%) (Razzak et al. 2011). The data indicates Bangladesh has very poor medical facility to promote a safe and worth life after having spinal cord injury. The study also pointed out some possible causes of poor life expectancy of person with SCI including inadequate acute management and lack of proper social reintegration (Razzak et al. 2011). Among a total of 1347 patients with spinal cord lesions admitted to the CRP there were 1059 (79%) spinal cord injuries due to trauma and 38% of them were tetraplegia. The most common site of injury was thoraco-lumber junction and lower cervical spine (Hoque, 2003).

Hoque, Grangeon & Reed (1999, pp. 858-860) suggested that most of the patients with SCI are between 20-40 years old and the overall age group ranged from 10-70 years. The male: female ratio was 7.5:1.0. They also mentioned that, fall from height is the first

common cause and carrying heavy weights on the head are the second main causes of SCI in Bangladesh. Among the traumatic spinal cord lesions, 60% are paraplegics and 40% are tetraplegic. Among the non-traumatic spinal cord lesions 84% are paraplegics and 16% are tetraplegic.

1.4. Caregiver:

There are caregivers who take care of children and adults and older people with disabling disease. Generally they are patients, wives, sibling, sons, daughters, close relatives, friends and neighbors. They assist patients in managing medications, therapies and medical emergencies; provide supervision, emotional support, assists in personal care, mobility and other basic daily living activities.

According to Oxford Advanced Learner's Dictionary (2001, p. 177) "Caregiver is a person who looks after a sick or old person".

When a person becomes injured with complete tetraplegic spinal cord injury they need caregivers for performing their personal activities. A complete tetraplegic patient with SCI loses sensory and motor function below the level of injury. So they become dependent on caregivers to assist them performing their daily living activities (Lindsey, 2003a, 2003b).

Different studies found that the disability of a family member is psychologically distressing for the informal caregivers of the family or close relatives. About 40% of patients with SCI need assistance in performing their important activities of daily living such as eating, dressing, personal hygiene, mobility etc and provide their emotional support and physical care as well. More than half of them are family members. Family members an important role in total health care system of a patient with SCI along with others health care professionals. They engaged themselves in care giving with or without preparation at all. They generally get little or no support or recognition for their great contribution for the person with SCI (Lindsey, 2003a, 2003b).

Caregivers for a person with SCI have to care for them for a long duration of time. This is because the life expectation for person with SCI is more than other chronic disease such as Alzheimer or AIDS. The caregivers of patient having SCI have to suffer from same problems for an indefinite time than other caregivers (Lindsey, 2003a; Information of patients, n.d.; Unalan et al., 2001, p. 319).

When one member of a family sustains a SCI then other family members become concerned about the treatment and prognosis of this injured person, which may create mental stress for them. They also have to think about money requirement for intervention, management transportation and changes in their home environment to make it accessible for that person. 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 (Rees, O'Boyle & MacDonagh, 2001).

Lindsey (2003a) also claimed that people with SCI become aggressive towards caregivers when they think that their needs are not being met as normal people. So they become frustrated as a result of impairing or losing their capability to perform their activities of daily living.

Research found that the quality of life of primary caregivers of a spinal cord injured victim is significantly affected some severity parameters related to the injury however do not seem to have an additional impact on the primary caregiver's life quality (Unalan et al., 2001, p. 318-322).

A similar study found that being female and having a child with mental health problems predicted caregiver anxiety and depression. In addition, having a child who was older at the time of injury predicted caregiver depression. Poor social relationships, having a caregiver with mental health problems and having a caregiver with less education predicted both child anxiety and depression (Kelly et al., 2011, p. 200-205).

Caregiver sex, child age at injury, and child mental health were related to caregiver outcomes. Caregiver education, marital status and child age were not. Caregiver mental health and education and child social relationships predicted child outcomes. Neither,

injury level nor injury severity was related to caregiver or child outcomes (Kelly et al., 2011, p. 200-205).

1.5. Demographic Information:

Building a relationship with parents and guardians and involving them in the location and selection of caregivers is very important. This section relating to caregivers should be completed by the caregivers or, by the social worker in consultation with the caregivers. It provides basic demographic information and contact details of the caregivers and their family. This information is important to the child/young person's family and it is provided to them unless identifying information could pose a risk to the personal safety of either the child/young person or the caregiver. Caregivers are informed before information about them is given to others, but they also talk to the supervisor if they are concerned about sharing this information. Care giving may be influenced by gender and by the expected caregiver roles within a family unit.

Demographic are current statistical characteristics of a population. Demographic characteristics of a population expressed statistically such as age, gender, educational level, social class, family size, religion, disabilities, mobility, home ownership, income level, occupation, nationality, marital status, working experience, working hour of the respondent continuously. A census is a collection of the demographic factors associated with every member of a population (National Institute of Health, 2012).

Family caregivers often feel unprepared, have inadequate knowledge, and receive little guidance from the oncology team for providing care to the SCI patient. Older caregivers are especially vulnerable because they may present with co morbidities, they may be living on fixed incomes, and their available social support networks may have shrunk. In addition, older caregivers of the patients may neglect their own health needs, have less time to exercise, forget to take their own prescription medications, and become fatigued from interrupted sleep. It is therefore common for care giving by older people to lead to poor physical health, depression, and even increased mortality. Younger caregivers must generally juggle work, their own family responsibilities, and sacrifices involving their

social lives. Middle-aged caregivers typically worry about missed workdays, interruptions at work, taking leaves of absence, and reduced productivity.

Age and its measurement are relatively non problematic, (the number of days, months and years since birth). But for some societies birth is not relevant, and dates of birth may not be known or be exact, to say nothing of differences in calendar. In this study I took the data after asking the participants' age.

Sex and gender are often used in the literature interchangeably and thus incorrectly. Sex refers to a biological entity; gender to social construction, and includes social, cultural or psychological dimensions.

Socio-economic status can be measured in a number of ways. The most common schemes relate to income, ownership of goods, type of and/or ownership/tenancy status of residence, classification of occupation, and educational attainment. Socio-demography exist, normally based on aggregate measures for the district in which individuals live and calculated on the basis of such variables as reality, housing density, accessibility of health and social services, income, employment, health and disability, education, skills and training, housing and services, living environment etc. It can be used as surrogates for individual data. For this study, CRP's own socioeconomic categories have been used.

Education is very important to both personal and professional life, in a number of significant ways.

A formal education of some sort is often paramount to future success. Completing increasingly advanced levels of education shows that you have a drive and commitment to learn and apply information, ideas, theories, and formulas to achieve a variety of tasks and goals. If the caregiver is properly educated he/she can guide the patient in a right way (National Institute of Health, 2012).

Family size is important because if the family size is big there is a possibility for a caregiver to be available. On the other hand if the family size is small the caregiver may

not be available and the family size also indicates the possibility of more or less family income.

Occupation of the caregiver is very important because this indicates how he/she can balance his/her occupation and the care of the patient. If the caregiver is very busy with his occupation he cannot concentrate on taking care of the patient properly.

It is important to know the marital status of the caregivers. Understandably an unmarried caregiver can give much more time than a married person because unmarried caregivers have less responsibility to the family and they can concentrate their work easily.

About 40% of patients with SCI need assistance in performing their important activities of daily living such as eating, dressing, personal hygiene, mobility and providing them emotional support and physical care as well. They depend on their caregivers. The information of demographic factor of caregivers of spinal cord injury is essential, because from this we will be able to know: who are the caregivers, what is the relationship between the caregiver and client, their age in years, their educational level, their culture and their socioeconomic condition. As community centered practice is a major role of occupational therapy so for this it is also necessary to gather caregiver's demographic information.

When occupational therapists know about the demographic factors of the caregivers then they can easily identify the caregivers' status and can give appropriate advice at their level. When the therapist can provide the appropriate advice at their level then the caregivers can easily understand the information within a short period of time. So, it is important to know the caregivers demographic factors of the therapist.

1.6. Significance of the study:

As this study fulfills its aim and objectives, it becomes helpful to look at the demographic factors of the caregivers of SCI patients at Centre for the Rehabilitation of the Paralysed (CRP), Savar. This study focuses on caregivers demographic factors that will help the professionals. The main focus of services provided by CRP is only on the patients and their quality of life.

There are caregivers who care for children and adults and older person with disabling diseases. Generally they are wives, sibling, sons, daughters, close relatives, friends and neighbors. They assist patients in managing medications, therapies and medical emergencies, provide supervision, emotional support, assist in personal care, mobility and other basic daily living activities. About 40% of patients with SCI need assistance in performing their important activities of daily living such as eating, dressing, personal hygiene, mobility etc and provide their emotional support and physical care as well (Lindsey,2003a, 2003b).

The caregivers are an important part of the rehabilitation team as described by different personnel. It is also important that, caregiver have an important role to handle the client. Generally the SCI client depends on their caregiver. During therapy session the therapist at first gives information to the caregiver for facilitating the treatment.

It is important to know about the demographic factors of the caregivers as it will provide good evidence for Occupational Therapy professionals in Bangladesh, and also help to improve quality of treatment outcomes in Occupational Therapy in this country. This research study will be of benefit to the Occupational Therapy Department at CRP, because most Occupational Therapist are conducting their clinical practice here, thus, the results may be applicable to them.

Demographic factors can be highlighted the relationships between the patients and their caregivers which may help to enhance the professionals in CRP, to those who are not aware the demographic characteristics of the caregivers.

If the occupational therapist knows the demographic factors of the caregiver it will be easier for the therapist to give instruction or training according to the level of the caregiver.

The therapist will understand the level of the caregiver and can provide profitable treatment advice. On the other hand the caregiver will be benefited because they will get the appropriate advice at their level and can easily grasp the information within short period of time.

By this study the professionals will be benefited to have a proper guideline to think their profitable treatment advice to their patient caregivers for facilitating the treatment. The people of the society would be able to get profitable treatment advice to the therapist and the patient caregivers will be benefited by receiving appropriate advice at their level.

1.7. Aim of the study:

To identify current demographic factors of caregivers of SCI patients in CRP.

In this chapter the methodology of the study will be discussed under the following aspects: design, setting, participants and sampling, measuring instrument, data collection procedure, data analysis, field test of semi structure questionnaire, ethical issues, reliability, and validity.

2.1. Study site:

The selected study site was the Spinal Cord Injury unit of Centre for the Rehabilitation of the Paralyzed (CRP), Savar, Dhaka. CRP's headquarters are in savar, approximately 25km from Dhaka, and the capital city of Bangladesh. The CRP is a non-governmental organization specializing in the management of patients with spinal cord lesions. It has 100 beds, and it provides free service to all the people in Bangladesh. Occupational therapist plays a major role in the treatment of SCI patients.

2.2. Participant:

The study participants were caregivers who were caring for spinal cord injury patients. The researcher selected participants who were providing care all the time and who were close relatives of the spinal cord injury patients. All of the SCI patients' caregiver was selected for this study that fulfilled the inclusion criteria. The researcher explained to every participant about the research aim. The researcher had taken sampling who were willingly participants in this research. The researcher selected participants in comprehensively. Finally, the investigator obtained 79 participants for this study who were giving care of the spinal cord injury patients.

2.3. Study design:

Cross sectional study design:

Cross-sectional study designs are carried out at one time point or over a short period. In a cross-sectional study, both outcomes and exposures are assessed on the individual's level. A cross sectional study can study a large number of participants at little cost or effort.

Data can also be collected on individual characteristics, alongside information about outcome. In this way cross-sectional studies provide a ‘snapshot’ of the outcome and the characteristics associated with it, at a specific point in time (Levin 2006, p. 24).

2.4. Inclusion criteria:

- The caregivers who come to the responsible person of the study willingly.
- The real relatives or family members are allowed to do the study.
- The caregivers who were giving care for SCI patients all the time.
- Male and Female caregivers.

2.5. Exclusion criteria:

- People who have no family relationship with a patient.
- Irregular caregivers are not allowed in this study.

2.6. Field testing of the semi structure questionnaire:

To make a feasible questionnaire the researcher translated the main questionnaires in Bengali. Then the researcher performed field testing with two people with caregivers of SCI patients. It was conducted to check the appropriateness of wording as well as easiness of understanding. The researcher had made a few changes in the wording of the questionnaire to make it suitable for the context of Bangladesh.

2.7. Data collection tools:

- Demographic Questionnaire:

Researcher collected these types of data by the specific demographic questionnaire: age, gender, relationships, marital status, family size, religion, education, occupation, income, patient diagnosis, and injury level patient gender.

- Pen and pencil

2.8. Data collection procedure:

Before collecting data the study aims and study procedures were explained to participants. They were given the opportunity to ask question and once they were satisfied they were asked to sign the written consent form. Once they signed the consent form the researcher completed the semi structure questionnaire with regards to demographic data. Researcher went to each participant's room to collect the data. In this stage researcher received help from a person who was a participant in this research. The researcher should be present to assist with specific demographic questionnaire items.

2.9. Data Analysis:

Firstly the researcher entered data from excel. Data was calculated in manually and then represents the data in the table. Demographic questionnaire analyzed & discussed about the demographic factors such as gender, age, caregiver's relation, marital status, family size, religion, education, Occupation etc. The relationships between patients & caregivers have been shown at cross tabulation chart by using SPSS software version 16.0.

Researcher finds out different level of age group among the study participants. For this research convenient researcher divided the gender level in to two parts such as male & female groups. The researcher divided the age level in to four parts such as up to 24 years in one age group, 25 to 34 is another age group, 35 to 44 years and 45 years or more than 45 years is another age group. The researcher divided the relationship in to five parts such as mother, wife, sister, brother and others. The study shows that the relationships status of

the most participants was related to wives. The researcher also finds out that most of the participants were married person. Researcher finds out different level of family size among the study participants. The researcher divided the family size in to four parts such as three or below than three is one group, 5 to 7 numbers is another group, 8 to 10 years & 10 or more than 10 numbers is another group. The researcher also finds out that most of the participants were Muslims.

The researcher also divides of educational level in to four parts such as no formal education, primary completed, Secondary completed, S.S.C level or above S.S.C level. The researcher also finds out caregivers family size, income injury level etc. The researcher finds out that most of the caregiver's patient was tetraplegic & complete level of injuries in this study. The relationships between patients' sex and caregivers' sex have been shown that most of the male and female patient's caregivers were female. They were the patient's mothers, wives, sisters, and others. The study also shown that most of the female caregivers provide care giving to the male patient but there were no male caregivers provide care giving for female patients.

2.10. Ethical consideration:

Approval was gained initially from Bangladesh Health Professions Institute. Inform consent paper will give to the individual participant during data collection session. A written consent form was signed by each participant after the study had been explained to them and any question that they had were answered to their satisfaction. The researcher assured them that their personal identify would be kept confidential and all the documents were kept in a safe place where only the researcher will have access. So, that there were no chance to break confidentiality and the research gave them assurance that participation in the study was entirely voluntary and participants knew that they could refuse to participate or stop participating at any time without that decision. Where data will be made public, as in publication, it will be presented in such a way that no individual person will be identifiable.

2.11. Reliability and validity:

- The semi structure questionnaire is a reliable and valid instrument.
- The semi structure question was individually discussed with each participant and full time for questions was given to them prior to completing the form.
- Semi structure questionnaire is perfect for assessing person with caregivers of SCI patients.

Socio – demographic characteristics of the respondents:

This study was aimed to find out the demographic factors by the caregivers of spinal cord injury patient with SCI at CRP, Savar. Difference between relationship in patient and caregivers as well as differences in patients' sex with the caregivers' sex of different relations with these patients were also tried to find out.

Researcher had taken total 79 participants where male participants were 8.86% (7 participants) & 91.14% (72 participants) were female and 96.20% (76 participants) of the participants were married and 3.710% (3 participants) of the participants were unmarried. Most of the participants were age range 35 to 44 years. Table 3.1. Shows that up to 24 years of participants were 5.06% (4 participants), 25 to 34 years of participants were 31.64% (25 participants), and 35 to 44 years of participants were 36.71% (29 participants) and more than 45 years of participants were 26.58% (21 participants).

According to this study out of 79 caregivers, there were mother 29.11% (23 participants), wives 53.16% (42 participants), sister 1.26% (1 participants), brother 3.710 (3 participants) and remaining 10 caregivers were others 12.65% (10 participants). They were son, daughters, grandmother, father, aunt, and mother in law. The relationships of the most participants were wives of the patients. Table 3.1.shows that most of the participants were Muslims 91.14% (72 participants) and very few numbers of participants were Hindu 8.86% (7 participants).

Table 3.1. shows that family sizes of the participants were 4 and below than 4 numbers of participants were 35.44% (28 participants), 5 to 7 numbers of participants were 49.37% (39 participants), and 8 to 10 numbers of participants were 13.92% (11 participants) and more than 10 numbers of participants were 1.26% (1 participants). The various family members were 5 to 7 numbers in 39 participants. Primary level education of the participants were 24.05% (19 participants), Secondary level education of the participants were 20.25% (16 participants), above S.S.C level education of the participants were 13.92% (11 participants) and no formal level of the education were 41.77% (33

participants). Here most of the caregivers were not educated. Table 3.1. shows that Occupation of the most participants were related to house wife, less than one third of the participants were others such as (tailor, businessman, student etc), a very few numbers of the participants were farmer, and a few numbers of participants were day labor and service holder.

As Table 3.1. Shown that, 87.34% (69 participants) was house wives, 3.710% (3 participants) was farmer, 1.26% (1 participant) was day labor, and 1.26% (1 participant) was service holder and 6.33% (5 participants) was others. Table 3.1. shows that income level of the participants were up to 3,000 taka 45.57% (36 participants) 3001 to 5000 taka of participants were 30.38% (24 participants), 5001 to 10,000 taka of participants were 15.19% (12 participants) and above 10,000 taka of the participants were 8.86% (7 participants). Most of the patients were tetraplegic 59.49% (47 participants) and others patients were paraplegic 40.50% (32 participants).

Table 3.1. Shows that most of the patients were complete 64.56% (51 participants) and others were incomplete 35.44% (28 participants). On the other hand table 3.1. Shows that most of the patients were male 89.87% (71 participants) and others were female 10.13% (8 participants). Table 3.2. Shows that among 79 participants there were 72 female caregivers and 7 male caregivers. Among these 72 female caregivers 64 women provide care giving to male patients and 8 women provide care giving to female patients. On the other hand it has been found from the study that all 7 male caregivers were belongs to 7 male patients. So, there were no male caregivers for female patients.

Table 3.3. Shows that among the 79 participants there were 71 male patients and 8 female patients. For the 71 male patients there were 19 mothers, 42 wives, 2 sisters, 3 brothers and others were 6 acted as the caregivers of the male patients. On the other hand for the 8 female patients there were 4 mothers and 4 others (such as aunts, grandmother, mother- in -law) were the caregivers of female patients but male caregivers were not present. The study shown that most of the female caregivers provide care giving to the male patient but there were no male caregivers provide care giving for female patients. They researcher finds out the results by calculated manually then showing the result in the table.

Table 3.1: Characteristics by socio-demographic factors of participants of spinal cord injury unit at CRP, Savar.

Characteristics	Number	Percent (%)
Sex		
Male	7	8.86%
Female	72	91.14%
Age		
Up to 24	4	5.06%
25-34	25	31.64%
35-44	29	36.71%
≥ 45	21	26.58%
Relation		
Mother	23	29.11%
Wife	42	53.16%
Sister	1	1.26%
Brother	3	3.710%
Others	10	12.65%
Marital Status		
Married	76	96.20%
Unmarried	3	3.710%
Family Size		
≤ 4	28	35.44%
5-7	39	49.37%
8-10	11	13.92%
>10	1	1.26%
Religion		
Muslim	72	91.14%
Hindu	7	8.86%

Occupation		
House wife	69	87.34%
Farmer	3	3.710%
Day labor	1	1.26%
Service holder	1	1.26%
Others	5	6.33%
Income		
Up to 3,000	36	45.57%
3,001-5,000	24	30.38%
5,001-10,000	12	15.19%
>10,000	7	8.86%

Diagnosis		
Tetraplegic	47	59.49%
Paraplegic	32	40.50%
Injury level		
Incomplete	28	35.44%
Complete	51	64.56%
Sex of the patient		
Male	71	89.87%
Female	8	10.13%

Table 3.2: The relationship between patients' sex with the caregivers' sex.

	Caregivers			
Patients		Female	Male	Total
	Female	8	0	8
	Male	64	7	71
		72	7	79

Table 3.3: The relationships between patients and caregivers.

Caregivers	Patients sex			
		Male	Female	Total
Mother		19	4	23
Wife		42	0	42
Sister		1	0	1
Brother		3	0	3
Others		6	4	10
		71	8	79

4.1. Socio-demographic characteristics of the participants:

Gender is an important factor of socio demographic characteristics. This study found that maximum participants were female 91.14% and 8.86% were male. This study mentioned above the number of female caregivers was more than male caregivers. According to Kelly et al. (2011, p. 200-205) reported that caregivers were mostly female in relationships between the psychological characteristics of youth with spinal cord injury patients. Kelly also reported their studies have shown 85% were female caregivers among youth with SCI patients. Unalan et al. (2001) reported that 84% of all primary caregivers were female in their studies.

Age is another important component of socio demographic characteristics. In this study majority of the participant's age were 35-44 years. Unalan et al. (2001), reported their studies fifty primary caregivers of spinal cord injury survivors in the community and 40 healthy controls of the same age were included in the study. Mean age were 38.26 ± 7.64 years in primary caregivers group and 37.30 ± 7.60 in healthy control group.

Caregiver's relationship status is another important component in this study. According to this study out of 79 caregivers, there were 79 caregivers from family. There were mother 29.11%, wives 53.16%, sister 1.26%, brother 3.710% and remaining 10 caregivers were others 12.65%. They were son, daughter, grandmother, father, aunt, and mother in law. The relationships of the most participants were wives of the patients. Kelly et al. (2011) report in a study that 203 caregivers, 78% were mothers, 14% were fathers, 5% were grandmothers, 1% were stepmothers, 1% were grandfathers and 1% were aunts.

Marital status is another important component of socio demographic characteristics. By this research total 96.20% participants were married and rests of them were unmarried in this study. Kelly et al. (2011) reported their studies have shown that 72% caregivers were married and 15% were divorced caregivers in youth with spinal cord injury patients. This study also focused that the caregivers who were wives also have to be worry about their

marital relationship with the patients. Unalan et al. (2001, p. 321) said that SCI may affect the marital relationship in the patient spouses. They feel stronger feelings of separation.

In this research total 79 participants were caregivers. From this study researcher found that among these 39 participants are from the family consisting of 5 to 7 numbers of family members. No society in the world is free from the influence of religion. In Bangladesh it is seen that the majority of the total populations are Muslims because traditionally Bangladesh is a Muslim dominated country. In this study found that the majority of the participants were Muslims 91.14% and others participants were Hindu 8.86%. Kelly et al. (2011) reports in a study have shown 78% participants were Caucasian.

Although a large portion of the participants were completed primary level of education and significantly numbers of participants were no formal education in this research. Here shows that 24.05% participants were primary level education and 41.77% were no formal education in this research. In this study most of the female caregivers were illiterate they were not engaged in work outside of home. They have little knowledge about patient's condition, the prognosis, what to do in critical situation, decision making and problem solving. They were dependent on male of their families.

It was said that in normal conditions female are generally take the task of care giving as they are less educated and dependent on male to meet their ongoing demands (Unalan et al. 2001, p. 321).

Kelly et al. (2011) report in a study that the ninety percent of caregivers did not complete high school, 23% graduated high school, 47% completed some college or an associate's degree and 21% completed a bachelor's degree or higher.

In Bangladeshi culture generally wives are house wives because they depend on their husbands for the economical purpose. So, in this study the researcher found that generally the main Occupation of the caregivers were household activities. A few numbers of caregivers were farmer, day labor, service holder, and others (businessman, student, tailor

ect). Socioeconomic statuses of the most caregivers were poor in this study. Most of the caregivers live from hand to mouth.

In this study found that the majority of the patients were tetraplegic 59.49% and others were paraplegic 40.50%. Md Fazlul Hoque et al. (1999, p. 858) report in a study that among the traumatic spinal cord lesions, 40% were paraplegic and 16% tetraplegics. Among the non-traumatic spinal cord lesion cause 84% were paraplegics and 16% tetraplegics. MS Islam et al. (2011) report that patients were mostly (93%) traumatic. Fifty-four percent had paraplegia and most common skeletal level segment was cervical (44%). Abdur Razzak et al. (2011) reported their studies have shown of the study populations of 158 persons, 86.1% had injuries of traumatic and 13.9% of non-traumatic origin, leading to 79.75% with paraplegia and only 20.25% with tetraplegia.

Majority of the SCI patients were complete level of injury 64.56% and incomplete level of Injury were 35.44% in this study. Sigita Mingaila et al. (2005) report in a study that the examination of patients has shown that 21 (15.4%) patients had complete injury (ASIA-A) in cervical injury in thoracic-lumber level. Thirty-five (25.7%) patients had incomplete injury in cervical area and 39 (28.7%) patients in thoracic-lumber level.

This study found that maximum patients were male 89.87% and 10.13% were female. According to Fazlul Hoque et al. (1999, p. 858) reported that most of the patient were between 20-40 years old and the overall age group ranged from 10-70 years. The male: female ratio was 7.5: 1.0. Abdur Razzak et al. (2011) report in a study that of the study population of persons with spinal cord injury treated in a rehabilitation centre at Dhaka, Bangladesh of 158 persons, 91% were males. Sigita Mingalia et al. (2005) reported that their study population consists of 97 (71.3%) males and 39 (28.7%) were females. At end of the discussion session the researcher can be said most of the SCI patients were males and very few numbers patients were females admitted to the centre for the rehabilitation of the paralysed and most of the patients caregivers were wives. The majority of the caregivers were not educated; they came from rural areas in Bangladesh and their socioeconomic conditions were very poor. The study also shown that most of the female caregivers provide care giving to the male patient but there were no male caregivers provide care giving for female patient.

4.2. Limitations of the study:

This study bears some limitations. This study was about the Identification of the demographic information of the caregivers while caring for SCI patients at CRP, Savar, in Bangladesh.

Though there were some limitations researcher was always keen about these limitations and considering these limitations researcher prepared this project on the Identification of the demographic information of the caregivers of patient having SCI at CRP, Savar.

- All of the samples were collected from CRP, Savar. It will be difficult to represent the whole caregivers of Spinal Cord Injury patients in Bangladesh and in community setting.
- There was not enough resource found of the caregivers of patients with SCI in Bangladesh. Any research on caregivers of patients with SCI will hardly be found in our perspective. So, no significant statistics and resources were not found to use in this study.

4.3. Conclusion:

This study was conducted with the aim to find out the demographic factors of the caregivers of Spinal Cord Injured patient in CRP. Caregivers are the integral part of health care system anywhere in the world for the person with SCI as well as other diseases. After completing this study it was seen that Spinal Cord Injured patients depend on their caregivers. Usually it is seen that the caregivers of the SCI patients have to care the patients for all day long. They assist patients in managing medications, therapies and medical emergencies; provide supervision and emotional support, assists in personal care, mobility, and other daily living activities. When a person becomes injured they need caregivers for performing their personal activities. After completing this study it was established that the relationships between patients and caregivers had been shown that most of the male and female patient's caregivers were female. They were the patient's mothers, wives, sisters, and others. The study also had been shown that most of the female caregivers provide care

giving to the male patient but there were no male caregivers provide care giving for female patients. So, it is important to encourage the male caregivers to participant in care giving activities of female patients and recommend that special training for caregivers of spinal cord injuries patients.

4.4. Recommendation of the study:

- Researcher recommends that future similar research will conduct in the broader area and large scale of sample size.
- It also needed to document caregivers demographic information.
- Researcher recommends that male caregivers need to be encouraged to participant in care giving activities of female clients.

Reference list

According to Harvard 2011 -

1. Bangladesh Bureau of statistics 2010-2011, Household income & expenditure survey, viewed 22 March 2013, <<http://siteresources.worldbank.org/BANGLADESHEXTN/Rrsources/295759-1312851106827/BDSummaryBrochure.pdf>>.
2. Ekman, L 2002, Neuroscience: Fundamental for Rehabilitation, 2nd edn, pp. 132-400, London: W.B. Saunders Company LTD.
3. FitzGerald, M.J.T 1995, Neuroanatomy: Basic and Clinical, 3rd edn, pp. 29-127, London: W.B. Saunders Company LTD.
4. Feinberg, S.D, & Miner, M 1997, Paralysis/ Spinal cord Introduction, Viewed 20 July 2012, <http://www.howardnations.com/spinal_cord/Spinal_cord_intro.html>.
5. Hollar, L.D 1995, 'Spinal cord injury' , in C.A. Trombly (ed), Occupational Therapy for physical Dysfunction, 4th edn, London: Williams and Wilkins, pp. 795.
6. Haque F, Grangeon, C & Reed, K 1999, 'Spinal cord lesion in Bangladesh and epidemiological study 1994-1995' , *Spinal cord journal*, vol.37, no3, pp. 857-860.
7. Hoque, F 2003, 'Spinal cord lesions in Bangladesh: an epidemiological study 1996-2000' , Paper presented at the 3rd Asian Spinal Cord Network Conference And the 4th Chiang Mai SCI Workshop, Chiang Mai, Thailand, 10-13 November.
8. Hornby, S.A. (Ed). 2001, Oxford Advanced Learners Dictionary of Current English 6th edn, Oxford: University Press.
9. Kelly, EH, Anderson, CJ, Garma, SI, Russel, HF, klaas, SJ, Gorzkowski, JA & vogel, LC 2011, 'Relationships between the psychological characteristics of youth with spinal cord injury and their primary caregivers', International Spinal Cord Society, Vol.49, pp. 200-205.

10. Lindsey, L 2003a, 'caregivers for SCI-SCI Infosheet # 17', Spinal Cord Injury Information Network, Viewed 10 November 2012, <<http://www.spinalcord.uab.edu/show.asp?durki=22479>>.
11. Lindsey, L 2003b, 'Personal Care Assistants, Spinal Cord Injury Information Network', Viewed 10 November 2012, <<http://www.spinalcord.uab.edu/show.asp?durki=29178>>.
12. Levin, K N 2006, Study design III: Cross-sectional studies, Dental Health Services Research Unit, University of Dundee, Dundee, Scotland, UK.
13. Momin, AKM 2003, 'Levels of Integration for People with Spinal Cord Injury in Bangladesh', viewed 10 November 2012, <<http://www.leeds.ac.uk/disabilitystudies/projects/phd-akmmomin.htm>>.
14. Mingaila, S & Krisciunas A 2005, 'Occupational therapy for patients with spinal cord injury in early rehabilitation', viewed 11 March 2012, <medicina.kmu.lt/0510/0510-05e.pdf>.
15. National Institutes of Health 2012, Family caregivers in cancer: Roles and Challenges, Viewed 29 August 2012, <<file:///C:/Users/pOltu/AppData/Local/Temp/page6%20%283%29.htm>>.
16. Osman, FA 2010, Health Policy, Programmes and System in Bangladesh: Achievements and Challenges, viewed 10 November 2012, <<http://sas.sagepub.com/content/15/2/263.abstract>>.
17. Razzak, ATM, Hellal, SA, Nuri, RP 2011, 'Life expectancy of persons with spinal cord injury (SCI) treated in Rehabilitation Centre at Dhaka, Bangladesh', *Asia Pacific Disability Rehabilitation Journal*, vol. 22, no. 2, viewed 10 November 2012, <<http://dcidj.org/article/view/34/40>>.
18. Rathore, FA 2011, Spinal Cord Injuries in the Developing World, viewed 9 November 2012, <<http://cirrie.buffalo.edu/encyclopedia/en/article/141/>>.

19. Rees, j, O'Boyle, C, & Donagh, R.M 2001, 'Quality of life: impact of chronic illness on the partner, J R Soc Med', Viewed 11 November 2012, <<http://www.jrsm.org/cgi/reprint/94/11/563>>.
20. Unalan, H, Gencosmanoglu, B, Akgun, K, Karamehmetoglu, S, Tuna, H, ones, k, Rahimpenah, A, Uzun, E & Tuzun F 2001, 'Quality of the life of primary caregivers of spinal cord injury survivors living in the community: controlled study with short form-36 questionnaire', international Medical society of paraplegia, Vol.39, pp. 318-322.
21. World Health Organization 2010, WHO Policy on the Employment of Persons with Disability, viewed 22 March 2013, <http://www.searo.who.int/LinkFiles_P/Personnel_Employment_of_Persons_with_Disabilities.pdf>.

Appendixes

18th November, 2012

To

The Course Coordinator

Occupational Therapy Department

Bangladesh Health Professions Institute

Center for the Rehabilitation of the Paralyzed

Chapain, Savar, Dhaka- 1343

Subject: Application for the approval of research Proposal

Sir,

With due respect and humble submission I beg most respectfully to state that I am a regular student of B. Sc. in Occupational Therapy. Now I am in 4th year. According to my academic curriculum I interested to do a research and the research title is "Identification of the Demographic information of the Caregivers of the person with SCI in CRP". I am sincerely seeking the approval of the research proposal.

I therefore pray and hope that you would be kind enough to approve my research proposal and will help me to complete my study successfully.


Your most obedient student,

Mst. Sabrina Sarwar 05.02.13

Mst. Sabrina Sarwar

B. Sc. in Occupational Therapy, 4th year, Roll No. - 17

BHPI, CRP, Savar.

Approved By	Signature
Course Coordinator & Research Supervisor Mohammad Mosayed Ullah Department of Occupational Therapy, BHPI, CRP, Savar, Dhaka-1343	<i>Approved</i> 

12th December, 2012

To

The In charge of the In-patient Unit

Occupational Therapy Department

Center for the Rehabilitation of the Paralyzed

Chapain, Savar, Dhaka- 1343, Bangladesh

Subject: Prayer for seeking permission to collect data from the SCI patients' caregivers of your unit.

Sir,

With due respect, I beg to state that I am a student of 4th year, enrolling in Bachelor of Science in Occupational Therapy at Bangladesh Health Professions Institute (BHPI), the academic institute of Centre for the Rehabilitation of the Paralyzed (CRP). At this stage, I am intending to collect data from the Caregivers of the Spinal cord injured patient in your Department. The data is for my dissertation which is as part of my Course module entitled **“What are the Demographic factors of the Caregiver of the person with SCI in CRP”**.

So, I therefore pray and hope that you would be kind enough to permit me to collect the data from the caregivers (Who match with my inclusion criteria of my study who are the real relatives or family members of SCI patient) of your Department and thus helping me to meet the partial fulfillment requirements of the Bachelor of Science in Occupational Therapy.

Sincerely yours,

Sabrina 12.12.12
.....

Mst. Sabrina Sarwar
4th year, Bachelor of Science in Occupational Therapy
Bangladesh Health Professions Institute
CRP- Chapain, Savar, Dhaka-1343

Approved By	Signature
Md. Iqbal Hossain In charge of In-patient Unit, Department of Occupational Therapy CRP- Chapain, Savar, Dhaka-1343	<i>Iqbal</i>

Consent form

This research is part of Occupational Therapy course and the name of the researcher is Mst. Sabrina Sarwar. She is a student of Bangladesh Health professions Institute (BHPI) in B. Sc. (Hons.) in Occupational Therapy in 4th year. The study was entitled as “What are the Demographic factors of the Caregiver of the person with Spinal cord Injury (SCI) unit at CRP, Savar.”

In this study I ama Participant

And I have been clearly informed about the purpose of the study. I will have the right to refuse in taking part any time at any stage of the study. For that reason I will not be bound to answer to anybody. This study has no connection with me and the treatment of my patient 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 the study will be kept safety and maintained confidently. Only the researcher will be eligible to access in the information for her publication of the research result. My name and address will not published anywhere of this study.

I can consult with the researcher and the research supervisor about the research process or get answer of any question regarding the research project.

I have been informed about the above mentioned information and I am willing to participate in the study with giving my consent.

Signature of the participant:	Date:
Signature of the Researcher:	Date:
Signature of the Witness:	Date:

Demographic Questionnaire

1. Gender of Caregiver:

- Male
- Female

2. Age of Caregiver (in years):

3. Duration of Care giving:

4. Relation to the patient:

5. Marital status: Yes/ No

6. If married, duration of marriage:

7. Family members:

8. Religion:

9. Educational level:

10. Occupation:

11. District Region:

12. Monthly income before Injury:

13. Type of patient: Paraplegic/ Tetraplegic

14. Level of Injury: Complete/ Incomplete

15. Date of accident:

16. Date of admission: