MUSCULOSKELETAL DISORDERS IN PRIMARY CAREGIVERS OF CHILDREN WITH CEREBRAL PALSY IN CENTER FOR REHABILITATION OF PARALYZED

By

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Submitted in Partial Fulfillment of the Requirements for the Degree of MSc in Rehabilitation Science

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Bangladesh Health Professions Institute (BHPI) Faculty of Medicine

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DECLARATION

- This work has not previously been accepted in substance for any degree and is not concurrently submitted in candidature for any degree.
- This dissertation is being submitted in partial fulfillment of the requirements for the degree of MSc in Rehabilitation Science.
- This dissertation is the result of my own independent work/investigation, except where otherwise stated. Other sources are acknowledged by giving explicit references. A Bibliography is appended.
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LIST OF ABBREVIATIONS AND ACRONYMS

ADLs: Activities of Daily living

BHPI: Bangladesh Health Professional Institute

BPT: Bachelors in Physiotherapy

CP: Cerebral Palsy

CRP: Center for Rehabilitation of Paralyzed

CSI: Caregiver Strain Index

Dr.: Doctor

HSC: Higher School Certificate

ICF: International Classification of Functioning, Disability and Health

IHT: Institute of Health Technology

IP: In patient

IRB: Institutional Review Board

MSDs: Musculoskeletal Disorders

N: Frequency/ number

NO. Number

OP: Out patient

SD: Standard Deviation

SPSS: Statistical Package for Social Science

SSC: Secondary School Certificate

QOL: Quality of life

WHO: World Health Organization

&: And

ABSTRACT:

Background: The primary care givers are the ones who take care of the child with CP like their mothers, grandmothers, aunties or aayas. Musculoskeletal disorders can be of various types such as neck pain, shoulder pain, elbow pain, wrist/ hand pain, upper back pain, low back pain, hip pain, knee pain and ankle pain. The children with CP may need complete assistance in their ADLs like eating, changing clothes, bathing, toileting, changing positions, walking and even standing needing permanent assistance by their primary caregivers significantly causing the musculoskeletal disorders to the caregivers. **Objectives:** To find out the presence, causes and types of MSDs in primary caregivers of the cerebral palsy children. **Methods:** A cross-sectional study was done. The primary caregivers of CP children at William & Marie Taylor School and others coming for the treatment at pediatric (IP & OP) department of CRP, Savar were the study population. There were 101 participants who performed face to face data collection procedures for CSI, Nordic Musculoskeletal Questionnaire and Socio-demographic Questionnaire. **Results:** It was found that most of the primary care givers of children with CP were their mothers (100%) which show that likely to the Asian culture the children are primarily cared by the female members of their family. The participants were mostly from Islamic religion (97%) having the system of consanguineous marriage and their related genetic causes. Most of the participants reside at rural part (59%) of the country. Most of these participants were found to have wrist/ hand disorders (77.3%). As mothers of children with CP are considered to be their primary caregivers and spend most of the time with them so they are mostly affected physically and psychologically. Conclusion: Musculoskeletal disorders were commonly seen in primary caregivers of CP child related to the care and services provided to them. Most of these caregivers were found to have wrist/ hand disorders among the nine types of disorders. For CSI among the maximum participants it was found to be that there have been work adjustments e.g., because of having to take time off.

Keywords: Musculoskeletal disorders, Cerebral palsy, Primary Caregivers, Caregiver Strain

CHAPTER I INTRODUCTION

1.1 Background

The vast spectrum of inflammatory and degenerative conditions mostly related to the muscles, tendons, ligaments, joints, peripheral nerves, and supporting blood vessels are considered as the musculoskeletal disorders. The inflammatory conditions such as tendon inflammations including tenosynovitis, epicondylitis and bursitis, nerve compression disorders such as carpal tunnel syndrome and sciatica and other related conditions like myalgia, low back pain and other pain syndromes without known pathology as well are considered as the conditions under musculoskeletal disorders. Although lower extremity has taken the major consideration in the recent days, the patients or subjects also complain about the body parts such as the low back, neck, shoulder, forearm, and hands also being commonly involved these days (Punnett & Wegman, 2004). Different types of work related musculoskeletal disorders such as low back pain, carpal tunnel syndrome, tendinitis, epycondilitis, etc. are related with different risk factors (Da Costa & Vieira, 2009).

Musculoskeletal disorders are universally prevalent among all age and gender groups, and their impact is pervasive (National Institute for Occupational Safety and Health (Cincinnati), 1997). Musculoskeletal pain is related to the considerable cause for morbidity among the people with major financial and sociological effects (Ortiz-Hernández, Tamez-González, Martínez-Alcántara, & Méndez-Ramírez, 2003). Complaints of musculoskeletal (MS) pain/discomfort are associated with physical disability, and it affects the health-related quality of life (S.M, S.S., & A.C.S., 2013). The work which requires physical involvement are the main causes for these kind of disorders as they mostly relate to heavy physical work such as lifting heavy weights, repetitive movements causing wear and tear of muscles, prolonged sitting and standing, excess turning and twisting movements (Habib et al., 2010).

Musculoskeletal disorders can be of various types such as low back pain, knee pain, shoulder pain, etc. and also can be very common among the primary caregivers. The primary care givers are the ones who take care of the child with CP like their mothers, grandmothers, aunties or aayas.

Cerebral palsy can be defined as the condition affecting the neurological system which is combined with non-progressive and non-contagious muscular related disorders causing physical disabilities and causing problems related to mobility. Cerebral palsy mainly occurs due to damage in the motor control centers and usually occurs at the time period of pregnancy, while delivering the child, immediately after the birth or about to the age of three. There are several types of cerebral palsy and they are mainly indicated by abnormality in muscle tone, abnormal or altered reflexes or motor development as well as coordination (Sharan, Ajeesh, Rameshkumar, & Manjula, 2010).

The person who takes care of their close and near ones when they cannot take care of themselves because of some medical conditions or any other related conditions, that person is said to be a primary caregiver. Primary caregiver can be anyone like parents, grandparents, friends, any relative, husband or wife and even nurses for those who acquire assistance in their ADL. These caregivers may or may not be educated or trained about the condition of the person they are taking care of. The professional and formal primary caregivers other than the family members or friends are even paid for their work as caring the people who need their assistance. The major roles performed by the primary caregivers are basically to help the people with their daily activities and spending much time with them in order to make them feel both physically and emotionally supported. Primary caregivers mostly try to find their happiness and work satisfaction by seeing the people they are serving happy (Stringfellow, n.d.).

As the care provided to all children must have various types of facilities which includes time, money, etc. So to care the children with disabilities will need more facilities. Here, the required facilities which are provided to care the children with disabilities have direct or indirect psychological as well as physical related impact to their primary caregivers as they have to spend more time with the children. CP has been found to be the most common conditions for disability seen in children. The children with cerebral palsy may need complete assistance in their ADL like eating, changing clothes, bathing, toileting, changing positions, walking and standing as well. These activities might need permanent assistance by their primary caregivers which may significantly cause the musculoskeletal disorders to the caregivers (Brehaut et al., 2004).

1.2 Justification:

As the cerebral palsy patients mainly have impairments with the motor functions, some of them may also have difficulties like sensation loss, communication problems, thinking capacity and other limitations in other activities related to daily living. The primary caregivers of those patients face many difficulties to provide the proper requirements for them. The primary caregivers of the patients with cerebral palsy have to go through more physical work out by themselves for providing the assistance to the children. The mothers of the cerebral palsy patients are considered to be the primary caregivers for them as the mothers are mainly affected by the children's habits and care giving demands. The daily needs of the children may cause many challenges and difficulties to the parents. The overall support from the society, other family members and neighbors also support the children in secondary way other than the support given by their primary care givers like their parents or close members of the family. The activities or support given by the care givers for the CP child in the house mainly focuses on the physical and psychological state which helps those child to overcome the stress and gain the self-efficacy techniques as well (Raina et al., 2005).

National Institute for Occupational Safety and Health (NIOSH), states that there were several epidemiological studies carried out for demonstration of the evidence of a mutual relationship between the physical exertion at work and work related musculoskeletal disorders (Bernard et al., 1997).

The prevalence of casual pain and discomfort related to musculoskeletal disorders are commonly seen in the caregivers of the cerebral palsy patients. The occurrence of mechanical back pain is usually seen in the primary care givers of the children with cerebral palsy because of repetitive lifting of the children. Hence, the trainings related to the lifting techniques, safe transferring and proper carrying techniques should be given to all the primary care givers timely. As the cerebral palsy children require the help and assistance in performing most of their daily activities. Hence, the parents or primary health care givers who are involved with them are needed to assist them by exerting themselves in different awkward posture, standing and carrying the child for longer time which acts as the risk factors causing the development of musculoskeletal disorders (Sharan, Ajeesh, Rameshkumar, &Manjula, 2010).

The severe cases of CP may cause the children to lose their control over trunk which further causes them to have problems with sitting, standing, walking and doing their other ADL independently. Use of wheelchair has been very helpful and productive for those children with severe CP as assistive device for mobility as well as for postural correction. Proper positioning of sitting in the wheelchair for those CP children can also prevent them from having any malformation of their joints and structures (Barks, 2004).

Children with CP using wheelchair can perform their skills regarding practical self reliant activities if they are positioned on their respective wheelchair comfortably by balancing their pelvis strongly on the seat. This technique can also lower the caregiver load as the children can develop their personal practical skills by themselves to perform most of their ADL (Rigby, Reid, Schoger, & Ryan, 2001).

1.3 Significance of the Study:

This study is believed to be the first of its kind to find out the disorders related to musculoskeletal system along with care giver stress index among the primary care givers of children with Cerebral palsy in Bangladesh. The main finding from this study will be to find out the presence, causes and types of MSDs in primary caregivers of the cerebral palsy children along with the causative factors that are associated for MSDs in the collected sample of participants. This study is expected to make the primary care givers more aware about their own disorders caused by their respective child with CP. Prevention, intervention and outcome regarding musculoskeletal symptoms can be considered for future studies.

1.4 Research Question:

 What are the types and factors related for the Musculoskeletal Disorders in primary caregivers of cerebral palsy children at William & Marie Taylor School and Pediatric unit (in and out patient department) of CRP, Savar, Bangladesh.

1.5 Operational Definition:

Cerebral Palsy (CP):

Cerebral palsy is basically known as the disorder related to various postural and movement dysfunctions caused due to permanent damage to the brain before birth, during birth or shortly after birth. It is mainly accompanied by the visual, sensory, communication, feeding, cognitive and behavioral impairments and difficulties. The cerebral palsy patients may require support in doing their daily activities from their primary caregivers as they will suffer from many postural and movement disorders. They can be dependent to their primary caregivers either fully or partially depending upon the types of cerebral palsy.

• Musculoskeletal disorders:

Musculoskeletal disorders are mainly described as the pain or any kind of injury in the musculoskeletal structure of an individual which may include the joints, muscles, ligaments, nerves, bones and tendons. It mainly affects the body movements. It mainly occurs due to over use, abnormal positioning, fatigue, repetitive stress, etc. to the musculoskeletal system of the body. Common musculoskeletal disorders are: mechanical back pain, thoracic outlet syndrome, sprains, strains, tendonitis, carpal tunnel syndrome, osteoarthritis and so on.

• Primary caregivers:

The primary caregivers are the persons who are primarily in charge or responsible for someone who cannot take care of themselves and are fully or partially dependent upon them. The primary caregivers can basically be any family members, parents, close friends or health professionals trained fully for the job of taking primary care of the individual. The primary care for an individual who needs the support can be helping them in their activities of daily living like: feeding, bathing, dressing them up, taking them for toileting, taking them out for medical checkups, taking them to the school or centers as well.

A case-control study done to find out the presence of musculoskeletal pain in the mothers as primary caregivers of the children with CP and also to show the relation between their pain and their QOL and also presence of depression concluded that low back pain is the most common musculoskeletal pain experienced by the mothers of CP children. Low back pain related to musculoskeletal disorder is commonly seen in the mothers as primary caregivers to children having cerebral palsy. The main cause of the pain seen in the mothers is because of the excess physical work while providing primary care to the cerebral palsy children. Psychological problems like depression seen in those mothers regarding the condition of their CP child caused more experience of low back pain by them. More pain significantly caused poor QOL of these mothers (Kaya et al., 2010).

According to different studies the burden coming on the way of primary caregivers of the cerebral palsy children causes affect to them both psychologically and physically (Musil, 1998; Raina et al., 2005). Raina et al (2004) concluded that the relationship between the child and their primary caregivers is very strong. The primary caregivers are much more emotionally attached with the child than any other member of the family. The condition of the child causes difference to the condition of their primary caregivers both physically as well as psychologically. Support from other family members and the society to the caregivers regarding their CP child is also found to be the major factor affecting the physical and psychological health of them. The needs of the CP child according to their conditions also affect the health condition and well being of their primary caregivers.

According to Muñoz-Marrón et al (2013) the degree of physical incapabilities, psychological issues and self-efficacy are the most common factors which causes hamper to the primary caregivers of the cerebral palsy children. The disability as well as dependency seen in the cerebral palsy children may be the most significant predictor for the burden to the primary caregivers of them.

An experimental study conducted to evaluate fatigue level in the mothers of CP children also to find out the related factors like clinical signs of CP, psychological disorders and quality of life determined the psychological health and declined quality of life in concern with physical, social and emotional aspects as well in the group of the mothers of cerebral palsy children concluded that there are higher chances of these conditions in the study group than those with healthy children. If these mothers are provided with some assistive devices for their CP child's assistance in daily life, for example: wheelchairs then they might get relieved from their own fatigue level to some extent (Garip et al., 2016).

A study conducted to identify the predictive factors of stress experienced by the mothers of cerebral palsy children in Bangladesh, concludes that Stress is experienced by a large number of mothers of CP children in Bangladesh. The problems in those CP children regarding their behaviors that include more time consumption of the mothers are the most strong predictive factors of the stress experienced by those mothers. The study suggested that these mothers of CP children felt a little relief of their stress by getting counseling about the management of the behavioral problems of their children. They were also relieved by the fact that they would get some practical help regarding the behavioral problems related to their children (Mobarak, Khan, Munir, Zaman & McConachie, 2000).

In 2012, Krstic & Oros conducted a study to find out the level of coping and adapting the stress in mothers of CP children. They concluded that reframing and coping with the stress level has been the most useful factors for stress adaptation by those mothers. Educational strategies are mostly utilized by the family members of the CP children with severe health conditions than those family members of CP

children with mild and moderate health conditions for stress adaptation. Indirect assessment of self has been practiced by the mothers of CP children residing at rural sides (Krstic & Oros, 2012).

A literature search done to review the factors related to the process of adaptation by the parents of CP children concluded that, the parents of CP children have to go through a lots of problems regarding the development of their children and the changing behavior of their family members towards these children and these factors affect the adaptation to their stress level (Rentinck, Ketelaar, Jongmans, & Gorter, 2007).

The parents of CP children are found to have more health abnormalities including physical as well as psychological than the parents of normal children. The parents who have access to regular health facilities with satisfied amount of income have higher chances of getting awareness about their health conditions and getting proper treatment and counseling on time. Some parents of CP children have low income and also some have higher expenses on their living because of providing facilities to those children which causes them to be away from medical facilities for themselves. These parents will earn just for expending on their CP children's facilities rather than for their own self (Brehaut et al., 2004).

A qualitative study conducted utilizing a grounded theory framework to find out the impact of care given to a CP child affecting the quality of life their parents concluded that, providing care and raising a CP child always creates both good and bad effects on their parents' life. Looking after the CP children influences or affects all the aspects of their parents' life which comprises their physical health, psychological condition, social interaction, level of freedom, family relationships, economic status and also their personal and professional lifestyles. Most of the parents of CP children suffer a lot in finding the financial as well as cooperation support from people and services regarding the condition of their children. Improving self economic condition and being more stable can be helpful in improving the QOL of these parents of CP children. In order to improve the QOL of parents of CP children for long term, awareness about the services, introduction

to the support groups, knowledge about the counseling sessions and provision of early intervention should be practiced in a well manner (Davis et al., 2010).

A case control study (2005) conducted to assess the QOL of mothers as primary caregivers of CP children stated that, the QOL and psychological state of the mothers of normal children are much higher than that of mothers of CP children. Healthy understanding relationship between the parents of CP children about the condition of their children and stable financial status of their family were found to be the most effective factors for improving the parents' psychological state and the QOL. The mothers of CP children restrict themselves and stay away from being involved in any activities, they give up to their personal interests as they are more focused and concerned about the condition of their child which affect their psychological state and QOL (Ones, Yilmaz, Cetinkaya, & Caglar, 2005).

A qualitative study using a grounded theory framework (2005) on parents' and CP children's perception on their QOL found out thirteen different aspects related to the QOL. The aspects are respectively; physical health, body pain and discomfort, ADL, social participation, emotions, interaction with community, communication, family health, environment, future, provision and access to services, economic condition and social well-being. These aspects should be fulfilled by the CP children in order to have a better QOL according to their parents and family members (Waters, Maher, Salmon, Reddihough, & Boyd, 2005).

Wu, Zhang, & Hong (2017) concluded that the QOL of primary caregivers of CP children is very less adequate compared to that of others, either they be mothers or grandmothers of those children. This unsatisfactory QOL of the primary caregivers is also related to their poor mental health and also poor physical functioning. The physical functioning is found to be poorer in grandmothers than the mothers as primary caregivers of those CP children.

TERZI & Tan (2015) found that, there is higher chance of presence of MSDs along with psychological problems in the mothers as primary caregivers of the CP children. MSDs are mostly common in the mothers of CP child of older ages as they require more assistance in their ADLs. Stress and depression also go hand in hand with the MSDs in these mothers because of the poor health condition of their child. Long term psychological imbalance in the body reduces the immunity which results in formation of different types of MSDs in the mothers.

A cross-sectional study was done for assessing the health condition of the primary caregivers of the CP children in Ireland in order to find out the risky ones among those caregivers. The study also concluded that the caregivers of the CP children have very poor health condition both physically and mentally as compared to other caregivers as they spend most of their time for taking care of their disabled child. If the CP children are given proper attention and adequate medical care with support then their caregivers' health condition can be made somewhat better. The caregivers of CP children who needed more assistance were found to have more complaint of physical pain and discomfort than those who needed less or no assistance (Byrne, Hurley, Daly, & Cunningham, 2010).

A cross-sectional study done at outpatient physiotherapy department for explaining the strain experienced by the mothers as primary caregivers of CP children reported that, Indian mothers having CP children usually show higher level of caregiver strain where the children needs more assistance for their ADL from these caregivers, and also they reside at the areas where there is less availability of any resources helpful for the assistance. The therapeutic professionals working for the CP children also suggest the family members of those children to work together in a team and community in order to provide them better care, services and assistance. The mothers who are primary caregivers of the CP children can get more knowledge and motivation about providing proper care to their children from the family and community team support without having more strain to them. Recruitment of more numbers of rehabilitation

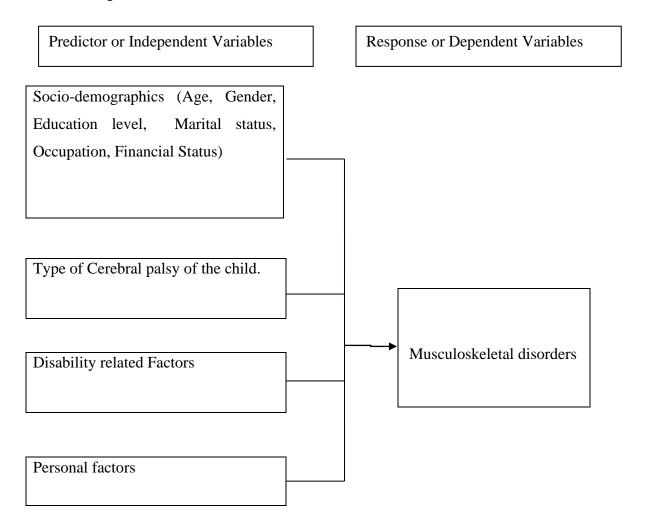
workers are requested to the health care policy makers in India (Prakash, Patel, Hariohm, & Palisano, 2016).

Neves, Pietrovski, & Claudino (2015) conducted a study to find out the correlation between back pain and QOL in primary caregivers of the CP children. They found that the primary caregivers of the CP children scored very low in the environment related aspect of their QOL. They concluded with negative correlation between back pain and QOL in those primary caregivers of CP children.

Sharan, Ajeesh, Rameshkumar, & Manjula (2012) found that MSDs are highly prevalent in primary caregivers of children with CP because they are responsible for the assistance of those children like shifting, carrying, transferring and holding as ADL. But, they concluded with no association of caregiver strain index between the study group (primary caregivers of CP children) and the other group (caregivers of children with other orthopedic problems). The cooperativeness of those CP children towards their primary caregivers was also found to be one of the major factors regarding prevalence of MSDs in the caregivers.

A qualitative interview method carried out with the mothers of CP children who are going for regular therapy sessions in Tamil Nadu, India found that mothers who are as a primary caregivers of the CP child not only face physical but also psychological and social challenges and strain. The mothers suffer many challenges without the support of their family members and husbands as well regarding the health condition of their CP child. They also face physical burden as they have to assist their child in their ADL. The mothers with low economic status of the family face more problems regarding the condition of their child than that of mothers of higher economic status. Most of them also suffer the problems and stigmas like isolation from their husband and family (Gopichandran, Vadivelan, Sekar, & Sru, 2020).

3.1 Conceptual Framework:



3.1.1 Variables:

Predictors or Independent Variables:

- Socio demographic Variables: It included age, gender, education level, marital status, occupation and financial status of the defined number of participants.
- **Type of Cerebral palsy of the child:** It included the type of cerebral palsy of the respective child of each participant.
- **Disability related Factors:** It included the types of assistive devices used by the CP child of the participants and also the age of the particular child.
- **Personal Factors:** It included the number of family members, presence of any chronic illness of the participants.

Responds or Dependent Variables:

 Musculoskeletal Disorders: Presence of any type of musculoskeletal disorders in the collected sample of participants related to their specific CP child.

3.2 Study Objectives:

General Objective:

 To find out the presence, causes and types of MSDs in primary caregivers of the cerebral palsy children at William & Marie Taylor School and Pediatric unit (in and out patient department) of CRP, Savar, Bangladesh.

Specific Objectives:

- To determine the types of MSDs present in the defined sample of the primary caregivers of cerebral palsy children.
- To find out the causative factors that are associated for MSDs in the collected sample of participants.
- To find out commonly involved joints and structures related to MSDs.
- To see/ assess the defined participant's technique of handling (lifting, carrying and holding) their CP child and other heavy objects without causing strain to themselves.

3.3 Study Design:

The research was a cross-sectional design. It followed quantitative approach to answer the research questions. Quantitative approach was used when researcher wants to quantify the problem and present result in numeric form.

3.4 Study Population:

The parents/ primary caregivers of Cerebral Palsy children at William & Marie Taylor School and those who are coming for the treatment at pediatric (in & out patients) department of CRP, Savar were the study population.

3.5 Study Area:

- William & Marie Taylor School, CRP, Savar
- Pediatric ward (in and outpatient department) of CRP, Savar.

3.6 Study Period:

The study period was for the duration of one year from July 2019 to July 2020 after approval of the research proposal. The study period included whole data collection and data analysis period.

3.7 Sampling technique and sample size:

-Technique:

The study used convenience sampling technique as it was effective according to the limited numbers of participants who could be the primary sources of data. The type of research design, aims and objectives of this study supported this sampling technique. This sampling technique was also easy to reach the study population according to inclusion and exclusion criteria.

-Size:

The formula for calculating the sample size is: n=Z 2 P (1-P)/d 2

Where, n denotes the sample size,

Z denotes the Z statistic for a level of confidence of 95%. So value of Z is considered 1.96

P=expected population as the overall point prevalence of Musculoskeleletal pain was 26.3% (Haq et al., 2005, p. 216-223).

d= 0.05 as precision, which is 5%

The sample size after the calculation using the formula and variables given above was found to be 292 but I collected the maximum of 110 data depending upon my time frame. The participants of my research study were the primary caregivers of the cerebral palsy children in CRP.

3.8 Inclusion and Exclusion Criteria

3.8.1 Inclusion Criteria:

- The persons (close family members, parents or aayas) giving primary care
 to the children having cerebral palsy who are studying at the William &
 Marie Taylor school and those who are coming for the treatment at
 pediatric (in & out patients) department of CRP, Savar.
- Participants having the CP child of age more than 2 years.
- Participants who signed the informed consent.

3.8.2 Exclusion Criteria:

- Participants who were not interested to be a part.
- Participants who were unable to respond to the instructions.
- Participants who were having any past medical history of musculoskeletal disorders other than associated with their CP child.

3.9 Data collection method (specific and details):

The data was collected after approval of the study by Dhaka University, Institutional Review Board of Bangladesh Health Professional Institute (BHPI) along with permission from Pediatric Department of CRP and William and Marie Taylor School, CRP. All the participants were explained about the purpose and procedure of the study before voluntarily agreeing to take part. Data were collected through face to face interview of prepared questionnaires. Before proceeding for the study, a pilot study was conducted at pediatric (in and out patients) department, CRP, Savar to find out possible drawbacks in the study tools and procedure and necessary correction was made to the best of possible knowledge and effort.

Data was collected from the participants using translated Bangla version of research instruments, Caregiver strain Index, Nordic Musculoskeletal Questionnaire and Socio demographic questionnaire. Data was collected by me with assistance of local friends by conducting interview. Questionnaire method was formulated for collection of data from the respondents. Self structured questionnaire was developed for collecting socio-demographic information of the respondents. The socio demographic questionnaire and Caregiver Strain Index along with the consent forms were translated by a 3rd year BPT Bangladeshi student of BHPI and back translated by a final year BPT Bangladeshi student of BHPI. I was able to get a Bengali translated version of Nordic Musculoskeletal Questionnaire from a research done by one of the ex-student of occupational therapy department, BHPI.

All these questionnaires were then judged by my supervisor Dr. Kamal Ahmed, Former Associate Professor, IHT, Mohakhali and approved by him for further process of data collection.

3.10 Data Analysis Procedure:

The data entry and analysis were done by using Statistical Package for Social Science (SPSS 25). Data was analyzed through descriptive statistical analysis and use them to generate tabulated reports, charts, plots of distributions, trends and other descriptive statistics and then other complex statistical analyses was conducted. A descriptive statistic was used to attain research objectives and represented through tables, histograms, bar graphs, pie charts and cross tables and required tests were performed accordingly.

Correlation Coefficients of different variables were conducted accordingly along with chi-square test for categorical variables.

3.11 Limitation of the study:

The presented study will be confined to only those participants who will be there at CRP, Savar during the time of study. So the possibility of participants who can give answer to the question can be missed. The study setting was selected keeping the limited time to collect data in mind.

3.12 Quality Control and Assurance:

To ensure and improve the quality of the study, first of all questionnaires were translated according to WHO guidelines i.e. first in the national language that is Bengali language following the standard procedure of linguistic validation. For translation, two individuals who were fluent in both languages were assigned for forward translation. They prepared two versions of questionnaires then sat together and discussed to come up with one first version of translated questionnaires. Then that translated version was provided to another person who is fluent in both languages and who have not seen the original copy of questionnaire for backward translation. Then all three translators finalized the final version of translated questionnaires for the study in Bengali language. Before starting data collection procedures, a pilot study was conducted at pediatric (in and out patients) department, CRP, Savar for the Questionnaires to ensure their face validity. All the questionnaires including socio demographic questionnaire, Caregiver Strain Index and Nordic Musculoskeletal Questionnaire were used in this pilot study. Filled questionnaires were kept safely. The data collected were reviewed, recorded and entered into the SPSS program in order to reduce the human errors which were likely to occur while entering and analysis of the data collected for this research.

3.13 Ethical Consideration:

Firstly, prepared research proposal was submitted to the concerning authority after getting approval from course coordinator of Department of Masters in Rehabilitation Science and supervisor. Ethical approval was taken from Institutional Review Board (IRB) of Bangladesh Health Professions Institute (BHPI) for conduction of research.

Individual informed consent was taken from participants before starting data collection. The participants were informed of their rights to leave or not give answer if they did not wish to answer any question within the questionnaire. Participants were not forced to answer the questions if they were not willing to. Appropriate informed consent was taken from the department heads respectively before conducting the study. Confidentiality and anonymity of the information provided by them was maintained. It is protected by the law "right to privacy" which prevents the researcher from disclosing any direct information about the participants of the research.

EXPECTED OUTCOME

The proposed research will help us to determine the presence of musculoskeletal pain in collected sample of participants who are the primary caregivers of the cerebral palsy children where the pain is caused due to different activities carried out in order to handling the CP. It will also help us to identify the types of musculoskeletal disorders in the primary caregivers of cerebral palsy children and also the commonly involved joints and structures. Moreover, it will also focus on the factors causing risks for musculoskeletal disorders in the primary caregivers. The information from this study may provide a basis for initiating future research.

CHAPTER IV RESULTS

Table 1. Showing Age range of the participants (n=110)

Age range	Frequency (n)	Percentage (%)	Mean	SD
16-20years	15	13.6	28.19	±7.506
21-25 years	36	32.7		
26-30 years	22	20.0		
31-35 years	21	19.1		
36-40 years	11	10.0		
41-45 years	1	0.9		
46-50years	4	3.6		
Total	110	100.0		

Table 1 represents the age range of the participants. It shows that participants with age group 41 to 45 years are less in number and the participants with age group 21 to 25 years old are more in this study. The frequency and percentage of ages is calculated and represented above. The mean for the age of the participants is 28.19 and standard deviation is ± 7.506 .

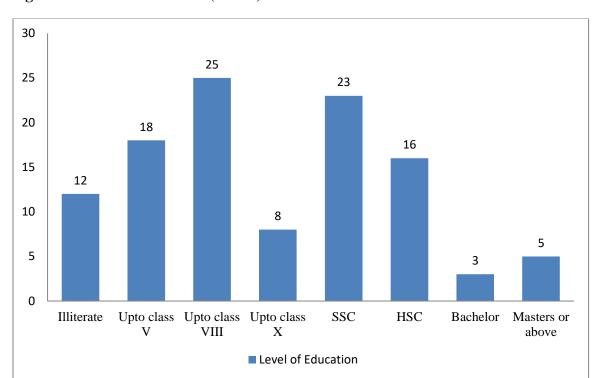


Figure 1. Level of Education (n=110)

The above figure of bar diagram represents the level of education of the participants. It shows that out of 110 samples for this study, 12 of them are illiterate, 18 of them studied up to class V, 25 up to class VIII, 8 up to class X, 23 of them have completed their SSC, 16 of them have completed their HSC, 3 of them have studied till their bachelors level and 5 of them have studied till masters and higher levels. The participants with education level up to class VIII are higher in number whereas, the participants with education level upto bachelors degree are least in number.

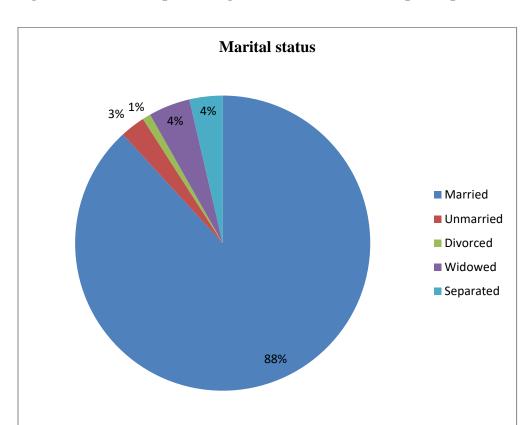


Figure 2. Pie-chart representing the marital status of the participants (n=110)

The above pie-chart represents the marital status of the participants. It shows that 88% of them are married, 4% separated, 4% widowed, 3% are unmarried and 1% divorced among the 110 participants. Maximum of the participants are married and minimum divorced.

Table 2. Showing the age range of the child (n=110)

Age range of the child	Frequency (n)	Percentage (%)	Mean	SD
2-6years	85	77.3	4.93	3.092
7-11years	19	17.3		
12-16years	6	5.5		
Total	110	100.0		

Table 2 represents the age range of the child with cerebral palsy of the participants. The frequency and percentage of the child's age is also shown here. There are maximum number of children within age range of 2 to 6 years and least number of children in the range of 12 to 16 years. The mean of the age of the children is 4.93. The standard deviation of the age of the children is 3.092 respectively shown in the table.

Table 3. Showing weight range of the child (n=110)

Wt range of child	Frequency (n)	Percentage (%)	Mean	SD
5-20kgs	95	86.4	1.17	0.466
21-36kgs	11	10.0		
37-52kgs	4	3.6		
Total	110	100.0		

Table 3 represents the weight range of the children with cerebral palsy of the participants. The table also shows the frequency, percentage, mean and standard deviation of the weight range of those children. The maximum number of children is in the range of 5 to 20kgs whereas the least number of children are in the range of 37 to 52kgs body weight. The mean weight of the children is 1.17 and the standard deviation of their weight is 0.466.

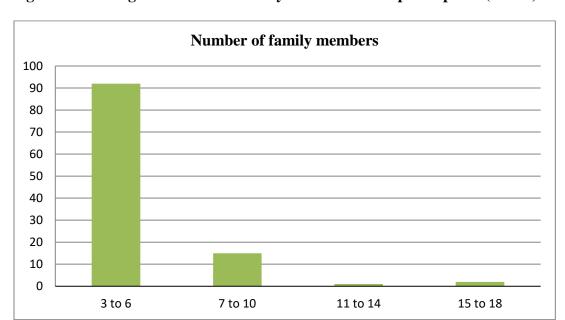


Figure 3. Showing the number of family members of the participants (n=110)

The above bar diagram represents the number of family members of the participants. It shows that out of 110 participants 92 of them have 3 to 6 members in the family, 15 of them have 7 to 10 members, 1 has 11 to 14 members and 2 have 15 to 18 members in the family respectively. There are maximum numbers of family members in 2 participants and least number of family members in 92 participants' family.

Table 4. Showing the monthly family income (in BDT) of the participants (n=110)

Family income	Frequency (n)	Percentage	Mean	SD
		(%)		
1001-10000	35	31.8	19414.55	13789.391
10001-20000	42	38.2		
21001-30000	18	16.4		
31001-40000	3	2.7		
41001-50000	10	9.1		
51001-60000	2	1.8		
Total	110	100.0		

Table 4 shows the monthly family income range in Bangladeshi taka of the participants. The table also shows the frequency, percentage, mean and standard deviation of their monthly family income. Maximum numbers of participants have the monthly family income of 10001 to 20000 taka and least numbers of participants have the monthly family income of 51001 to 60000 taka. The mean of the family income of the participants is 19414.55. The standard deviation of the family income of the participants is 13789.391 as shown in the table above.

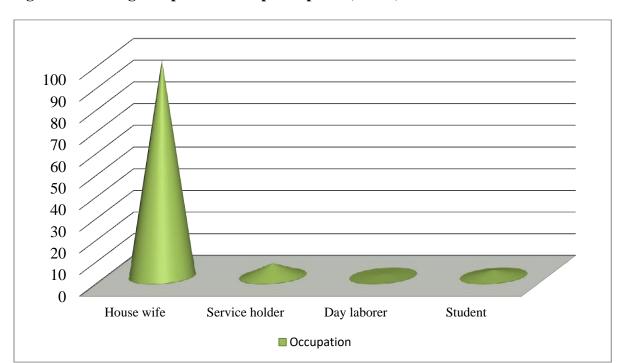
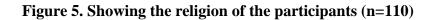
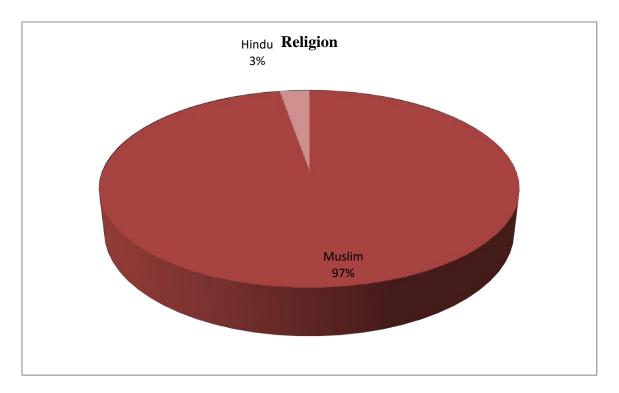


Figure 4. Showing occupation of the participants (n=110)

The above figure of bar diagram represents the distribution of occupation of the participants. It shows that out of 110 participants, 100 of them are housewives, 6 of them are service holder, 1 of them is a day laborer and 3 of them are students. There are maximum numbers of house wives and least number of day laborer among the participants.





The above pie-chart represents the distribution of religion of the participants. It shows that maximum of them 97% are Muslims and remaining 3% are Hindus.

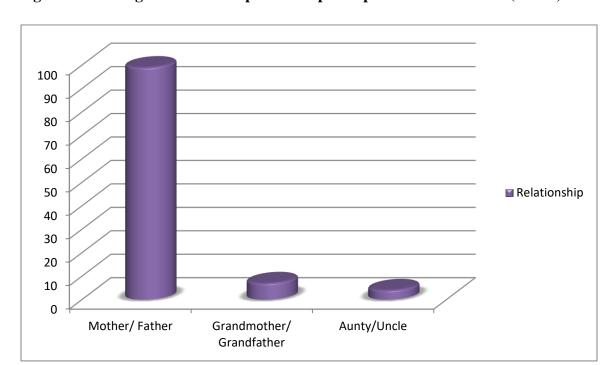


Figure 6. Showing the relationship between participants and their child (n=110)

The bar-diagram above represents the relationship of the participants with their respective child. It shows that out of 110 participants 99 of them are mothers as primary caregivers, 7 of them are grandmothers and 4 of them are aunties of those child.

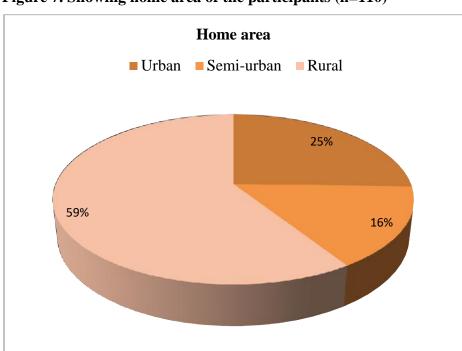


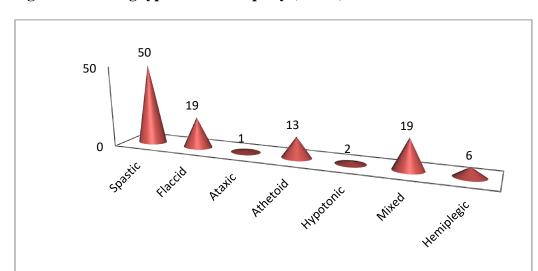
Figure 7. Showing home area of the participants (n=110)

The above pie-chart represents the distribution of home area of the participants. It shows out of total, 100% of the participants 59% resides in rural area, 25% in urban area and 16% in semi-urban area respectively. Maximum numbers of participants are residing in rural area and less are residing in semi-urban area.

Table 5. Showing the types of assistive device used by the child (n=110)

Assistive Device used by	Frequency (n)	Percentage (%)
the Child		
Chair/seat	11	10.0
Orthotic Devices	16	14.5
Frames	7	6.4
Back slab	3	2.7
Do not use	73	66.4
Total	110	100.0

The table above shows the distribution of assistive device used by the CP child of the participants. According to the table, out of 110 children of the participants respectively 11 of them use chair or seat as assistive device, 16 use orthotic devices, 7 use frames, 3 use back slab and 73 of them do not use anything. It shows that maximum children out of the total sample do not use any type of assistive devices whereas very less of them use back slab for their assistance. The percentage of the children using assistive devices is also mentioned in the table according to their frequency.



■ Type of CP

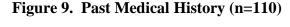
Figure 8. Showing type of cerebral palsy (n=110)

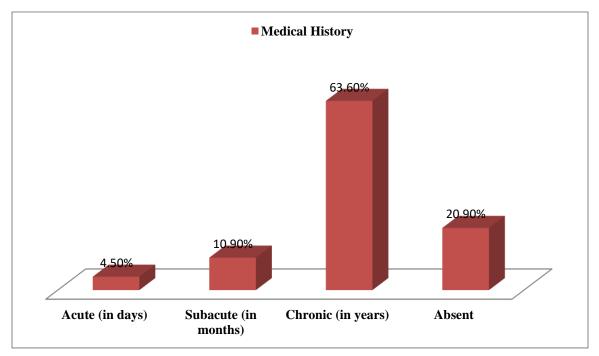
The bar-diagram above represents the distribution of type of cerebral palsy of the child of the participants. The figure shows that out of 110 children, 50 are spastic CP, 19 are flaccid CP and mixed CP respectively, 1 is ataxic CP, 13 are athetoid CP, 2 are hypotonic CP and 6 are hemiplegic CP. The figure explains that maximum numbers of children are spastic CP and least is ataxic CP. There are 19 children each in flaccid CP and mixed CP condition.

Table 6. Present Illness of the participants (Caregivers) (n=110)

Illness	Frequency (n)	Percentage (%)
Musculoskeletal	95	86.4
Neurological	1	0.9
Absent	12	10.9
Musculoskeletal+Neurological	2	1.8
Total	110	100.0

The table above represents the distribution of the presence of illness in the participants. It shows that out of 110 participants 95 of them have musculoskeletal illness, 1 of them has neurological illness, 12 of them do not have any type of illness and 2 of them have both musculoskeletal and neurological illness. The table also shows the percentage distribution of present illness in the participants. The maximum numbers of participants are having musculoskeletal illness whereas minimum having neurological illness.





The above mentioned bar-diagram represents the distribution of presence of past medical history in the participants (in percentage). It shows that 63.60% of the total participants have chronic (since years) illness, 10.90% of them have subacute (since months) illness, 4.50% of them have acute (since days) illness and 20.90% do not have any type of past medical history. The mentioned figure explains that maximum of the participants are having chronic illness since years and least of them are having acute illness since days.

Table 7. Type of Chronic Illness in participants (n=110)

Chronic Illness	Frequency (n)	Percentage (%)
Cardiovascular	3	2.7
Respiratory	6	5.5
Blood	10	9.1
Infectious	2	1.8
Inflammatory	2	1.8
Metabolic and Endocrine	6	5.5
Absent	81	73.6
Total	110	100.0

The above frequency table represents the distribution of presence of type of chronic illness in the participants. It shows that out of 110 participants, 3 of them have cardiovascular diseases, 6 of them have respiratory diseases, 10 of them have blood related diseases, 2 of them have infectious disease and also other 2 of them have inflammatory diseases, 6 of them have metabolic and endocrine diseases but 81 of them do not have any type of the chronic illness. Maximum numbers of participants do not have complaint of any type of chronic illness and very less participants are having complaint of infectious and inflammatory diseases as a chronic illness. The above mentioned table also presents the percentage of the frequency of the participants having complained of types of chronic illness.

Table 8. Characteristics of CSI and MSD (n=110)

QUESTIONS	CORRECT NUMBER	CORRECT PERCENTAGE
CSI:	NUMBER	FERCENTAGE
Sleep is disturbed (e.g., because is in and out of bed or wanders around at night)	66	60
It is inconvenient (e.g., because helping takes so much time or it's a long drive over to help)	29	26.4
It is a physical strain (e.g., because of lifting in and out of a chair; effort or concentration is required)	18	16.4
It is confining (e.g., helping restricts free time or cannot go visiting)	59	53.6
There have been family adjustments (e.g., because helping has disrupted routine; there has been no privacy)	42	38.2
There have been changes in personal plans (e.g., had to turn down a job; could not go on vacation)	96	87.3
There have been emotional adjustments (e.g., because of severe arguments)	63	57.3
Some behavior is upsetting (e.g., because of incontinence; has trouble remembering things; or accuses people of taking things)	41	37.3
It is upsetting to find has changed so much from his/her former self (e.g., he/she is a different person than he/she used to be)	56	50.9
There have been work adjustments (e.g., because of having to take time off)	97	88.2
It is a financial strain	42	38.2
Feeling completely overwhelmed (e.g., because of worry about, concerns about how you will manage)	16	14.5
MSD:		
Have you at anytime during last 12 months had trouble (such as ache, pain, discomfort, numbness) in: Neck	59	53.6
Have you had trouble during the last 7 days in the Neck	32	29.1
During the last 12 months have you been prevented from carrying out normal activities (eg. job, house work,	14	12.7
hobbies) because of this trouble in the Neck Have you at anytime during last 12 months had trouble (such as ache, pain, discomfort, numbness)in Shoulders	13	11.8

Have you had trouble during the last 7 days in the Shoulders	9	8.2
During the last 12 months have you been prevented from carrying out normal activities (eg. job, house work, hobbies) because of this trouble in the Shoulders (both or either)	6	5.5
Have you at anytime during last 12 months had trouble (such as ache, pain, discomfort, numbness) in: Elbows	5	4.5
Have you had trouble during the last 7 days in the Elbows	3	2.7
During the last 12 months have you been prevented from carrying out normal activities (eg. job, house work, hobbies) because of this trouble in the Elbows (both or either)	6	5.5
Have you at anytime during last 12 months had trouble (such as ache, pain, discomfort, numbness) in: Wrist/Hands	8	7.3
Have you had trouble during the last 7 days in the Wrist/ Hands	7	6.4
During the last 12 months have you been prevented from carrying out normal activities (eg. job, house work, hobbies) because of this trouble in the Wrist/ Hands (both or either)	8	7.3
Have you at anytime during last 12 months had trouble (such as ache, pain, discomfort, numbness) in: Upper back	57	51.8
Have you had trouble during the last 7 days in the Upper back	39	35.5
During the last 12 months have you been prevented from carrying out normal activities (eg. job, house work, hobbies) because of this trouble in the Upper back	12	10.9
Have you at anytime during last 12 months had trouble (such as ache, pain, discomfort, numbness) in: Lower back	84	76.4
Have you had trouble during the last 7 days in the Lower back	69	62.7
Have you at anytime during last 12 months had trouble (such as ache, pain, discomfort, numbness) in: Hips/thighs/buttocks	28	25.5
Have you had trouble during the last 7 days in the Hips/thighs/buttocks	15	13.6

During the last 12 months have you been prevented from carrying out normal activities (eg. job, house work, hobbies) because of this trouble in the Hips/thighs/buttocks	3	2.7
Have you at anytime during last 12 months had trouble (such as ache, pain, discomfort, numbness) in: Knees	44	40
Have you had trouble during the last 7 days in the Knees	32	29.1
During the last 12 months have you been prevented from carrying out normal activities (eg. job, house work, hobbies) because of this trouble in the Knees	13	11.8
Have you at anytime during last 12 months had trouble (such as ache, pain, discomfort, numbness) in: Ankles/Feet	31	28.2
Have you had trouble during the last 7 days in the Ankles/Feet	19	17.3
During the last 12 months have you been prevented from carrying out normal activities (eg. job, house work, hobbies) because of this trouble in the Ankles/Feet	4	3.6
Neck Disorder	52	47.3
Shoulder Disorder	67	60.9
Elbow Disorder	84	76.4
Wrist/Hand Disorder	85	77.3
Upper Back Disorder	53	48.2
Low Back Disorder	25	22.7
Hip Disorder	82	74.5
Knee Disorder	65	59.1
Ankle Disorder	78	70.9

The frequency table represents the distribution of characteristics of the Caregiver Strain Index and Nordic Musculoskeletal Questionnaire. It shows that sleep is disturbed (e.g., because the child is in and out of bed or wanders around at night) for 66 participants, It is inconvenient (e.g., because helping takes so much time or it's a long drive over to help) for 29 participants, It is a physical strain (e.g., because of lifting in and out of a chair; effort or concentration is required) for 18 participants, It is confining (e.g., helping restricts free time or cannot go visiting) for 59 participants, There have been family adjustments (e.g., because helping has disrupted routine; there has been no privacy) for 42 participants, There have been changes in personal plans (e.g., had to turn down a job;

could not go on vacation) for 96 participants, There have been emotional adjustments (e.g., because of severe arguments) for 63 participants, Some behavior is upsetting (e.g., because of incontinence; the child has trouble remembering things; or the child accuses people of taking things) for 41 participants, It is upsetting to find the child has changed so much from his/her former self (e.g., he/she is a different person than he/she used to be) for 56 participants, There have been work adjustments (e.g., because of having to take time off) for 97 participants, It is a financial strain for 42 participants and Feeling completely overwhelmed (e.g., because of worry about, concerns about how you will manage) for 16 participants out of 12 twelve characteristics mentioned in Caregiver Strain Index.

For the characteristics of Nordic Musculoskeletal Questionnaire, the table shows that there were 52 participants with Neck Disorders, 67 participants with Shoulder Disorders, 84 participants with Elbow Disorders, 85 participants with Wrist/Hand Disorders, 53 participants with Upper Back Disorders, 25 participants with Low Back Disorders, 82 participants with Hip Disorders, 65 participants with Knee Disorders and 78 participants with Ankle Disorders.

Table 9. Showing total CSI score and frequency of the participants (n=110)

Score	Frequency	Percent (%)	
0	1	0.9	
1	1	0.9	
2	3	2.7	
3	8	7.3	
4	13	11.8	
5	14	12.7	
6	17	15.5	
7	15	13.6	
8	21	19.1	
9	9	8.2	
10	3	2.7	
11	4	3.6	
12	1	0.9	
Total	110	100	

The above mentioned frequency table showed the number and percentage of participants having the scores involved in Care giver Strain Index as per the questionnaires involved. Out of twelve questions and having the scores as Yes=1 and No=0 the total number of participants (110) were found to have; 21 of them got a score of 8 followed by 17 of them got 6, 15 of them got 7, 14 of them got 5, 13of them got 4, 9 of them got 9, 8 of them got 3, 4 of them got 11, 3 of them got 10 and other 3 got 2, 1 of them got 12, the other 1 got 1 and lastly 1 of them got 0. Any positive answer indicated a need for intervention in that area as a score of 7 or higher indicates a high level of strain in those care givers (participants).

Table 10. Correlation between Age of Child and socio demographic data (n=110)

Primary care givers	Correlation coefficient	P value
Age	.319	0.001
Marital status	0.044	.650
Education	085	.377
Occupation	0.059	.540
Relationship with child	.048	.619

The above mentioned table shows the correlation between the age of the child and socio demographic data of the participants. It shows that there is positive correlation between the age of the child and the age of their primary care givers (0.001) whereas it is not correlated to the marital status (0.650), education level (0.377), occupation (0.540) and relationship (0.619) of the primary care givers.

Table 11. Correlation between types of cerebral palsy and socio demographic data (n=110)

Primary care givers	Correlation coefficient	P value
Age	020	.839
Marital status	096	.319
Education	.085	.380
Occupation	124	.197
Relationship with child	139	.149
Home area	084	.382

The above mentioned table shows the correlation between the types of Cerebral palsy and socio demographic data of the participants. The table shows that there is no correlation between the type of cerebral palsy to the age (0.839), marital status (0.319), education level (0.380), occupation (0.197), relationship (0.149) and home area (0.382) of the primary care givers.

Table 12. Correlation between weight and its socio demographic data (n=110)

Primary care givers	Correlation coefficient	P value
Age	.219	.022
Marital status	045	.643
Education	.003	.979
Occupation	070	.469
Relationship with child	116	.227
Home area	169	.077

The above mentioned table shows the correlation between the weight of the child and socio demographic data of the participants. The table shows that there is positive correlation between the weight of the child to the age (0.22) of their primary care givers but no correlation between their weight and marital status (0.643), education level (0.979), occupation (0.469), relationship (0.227) and home area (0.077) of the primary caregivers.

Table 13. Correlation between assistive device and its socio demographic data (n=110)

Primary care givers	Correlation coefficient	P value
Age	.132	.170
Marital status	.042	.664
Education	112	.243
Occupation	.076	.431
Relationship with child	.166	.083
Home area	.527	.000

The above mentioned table shows the correlation between the assistive devices used by the children with CP and socio demographic data of the participants. The table shows that there is highly positive correlation between the use of assistive devices by the cerebral palsy children to the home area (0.000) of their primary care givers where as no significant correlation between the use of assistive devices by them to the age (0.170), marital status (0.664), education level (0.243), occupation (0.431) and relationship (0.083) of their primary care givers.

Table 14. Cross Tabulation among the types of MSDs and home area (n=110)

Variables		Home Area		Chi Square	P value
Neck Disorder	Urban	Semi Urban	Rural	7.508	0.023
Yes	25.0%	52.9%	55.4%		
No	75.0%	47.1%	44.6%		
Shoulder				2.182	0.336
Disorder					
Yes	50.0%	58.8%	66.2%		
No	50.0%	41.2%	33.8%		
Elbow Disorder				2.622	0.270
Yes	71.4%	64.7%	81.5%		
No	28.6%	35.3%	18.5%		
Wrist/Hand				4.624	0.099
Disorder					
Yes	75.0%	58.8%	83.1%		
No	25.0%	41.2%	16.9%		
Upper Back Disorder				1.339	0.512
Yes	39.3%	47.1%	52.3%		
No	60.7%	52.9%	47.7%		
Low Back Disorder				2.298	0.317
Yes	14.3%	17.6%	27.7%		
No	14.3% 85.7%	82.4%	72.3%		
	03.170	02. r/0	12.5/0	205-	0.4
Hip Disorder				3.875	0.144
Yes	60.7%	76.5%	80.0%		
No	39.3%	23.5%	20.0%		
Knee Disorder				8.541	0.014
Yes	35.7%	64.7%	67.7%		
No	64.3%	35.3%	32.3%		
Ankle Disorder				7.987	0.018
Yes	50.0%	76.5%	78.5%		
No	50.0%	23.5%	21.5%		

The above mentioned table represents the cross tabulation for presence of different types of Musculoskeletal disorders in the participants depending upon their home area. The table shows that among the nine types of musculoskeletal disorders divided according to the site of disorders only neck disorders (0.023), knee disorders (0.014) and ankle disorders (0.018) had significant association with the home area they reside. But no significant association between shoulder disorders (0.336), elbow disorders (0.270), wrist/hand disorders (0.099), upper back disorders (0.512), low back disorders (0.317) and hip disorders (0.144) and the home area the participants reside at.

Table 15. Cross Tabulation among the types of MSDs and weight of the child (n=110)

Variables	Weight of	the child (%)		Chi Square	P value
Neck Disorder	5-20kgs 21-36kgs		37-52kgs	1.962	0.375
Yes	49.5%	27.3%	50%		
No	50.0%	72.7%	50%		
Shoulder Disorder				5.706	0.058
Yes	65.3%	36.4	25		
No	34.7	63.6	75		
Elbow Disorder				1.744	0.418
Yes	77.9	72.7	50		
No	22.1	27.3	50		
Wrist/Hand				1.844	0.398
Disorder					
Yes	77.9	81.8	50		
No	22.1	18.2	50		
Upper Back				1.770	0.413
Disorder					
Yes	48.4	36.4	75		
No	51.6	63.6	25		
Low Back Disorder				1.295	0.523
Yes	24.2	9.1	25		
No	75.8	90.9	75		
Hip Disorder				2.583	0.275
Yes	76.8	54.5	75		
No	23.2	45.5	25		
Knee Disorder				6.656	0.036
Yes	60.0	72.7	0.0		
No	40.0	27.3	100.0		
Ankle Disorder				4.742	0.093
Yes	71.6	81.8	25		
No	28.4	18.2	75		

The above mentioned table represents the cross tabulation for presence of different types of Musculoskeletal disorders in the participants depending upon the weight of their child

with CP. It shows that among those nine types of musculoskeletal disorders only knee disorders had the significant association with the weight of the respective child which is 0.036. Whereas, there was no association between the neck disorders (0.375), shoulder disorders (0.058), elbow disorders (0.418), wrist/hand disorders (0.398), upper back disorders (0.413), low back disorders (0.523), hip disorders (0.275) and ankle disorders (0.093) with the weight of their respective CP child.

Table 16. Cross Tabulation among the types of MSDs and Assistive Devices used by the child (n=110)

Variables	Assistive D	evices used	by the chi	ld (%)		Chi square	P Value
Neck Disorder	Chair/Seat	Orthotics	Frames	Backslab	Not use	5.515	0.238
Yes	45.5	31.3	42.9	0.0	53.4		
No	54.5	68.8	57.1	100.0	46.6		
Shoulder Disorder						7.231	0.124
Yes	27.3	62.5	85.7	66.7	63.0		
No	72.7	37.5	14.3	33.3	37.0		
Elbow Disorder						1.125	0.890
Yes	72.7	75.0	71.4	100.0	76.7		
No	27.3	25.0	28.6	0.0	23.3		
Wrist/Hand						1.971	0.741
Disorder							
Yes	81.8	68.8	85.7	100.0	76.7		
No	18.2	31.3	14.3	0.0	23.3		
Upper Back Disorder						4.094	0.393
Yes	27.3	50.0	28.6	33.3	53.4		
No	72.7	50.0	71.4	66.7	46.6		
Low Back Disorder						5.540	0.236
Yes	18.2	12.5	0.0	0.0	28.8		
No	81.8	87.5	100.0	100.0	71.2		

Hip Disorder						8.976	0.062
Yes	63.6	87.5	42.9	33.3	78.1		
No	36.4	12.5	57.1	66.7	21.9		
Knee Disorder						5.218	0.266
Yes	36.4	50.0	85.7	66.7	61.6		
No	63.6	50.0	14.3	33.3	66.4		
Ankle Disorder						5.247	0.263
Yes	63.6	68.8	100.0	33.3	71.2		
No	36.4	31.2	0.0	66.7	28.8		

The above mentioned table represents the cross tabulation for presence of different types of Musculoskeletal disorders in the participants depending upon the assistive devices used by the children with CP. The table shows that among the nine types of MSDs divided according to the site of disorders as neck disorders (0.238), shoulder disorders (0.124), elbow disorders (0.890), wrist/ hand disorders (0.741), upper back disorders (0.393), low back disorders (0.236), hip disorders (0.062), knee disorders (0.266) and ankle disorders (0.263) there is no significant association between these MSDs and assistive devices used by the CP child.

Table 17. Cross Tabulation among the types of MSDs and Number of Family members (n=110)

Variables	Numbe	r of Family	members ((%)	Chi Square	P value
Neck Disorder	3-6	7-10	11-14	15-18	5.050	0.168
Yes	45.7	66.7	0.0	0.0		
No	54.3	33.3	100.0	100.0		
Shoulder Disorder					7.263	0.064
Yes	55.4	86.7	100.0	100.0		
No	44.6	13.3	0.0	0.0		
Elbow Disorder					1.133	0.769
Yes	75.0	80.0	100.0	100.0		
No	25.0	20.0	0.0	0.0		
Wrist/Hand					7.848	0.049
Disorder						
Yes	77.2	86.7	100.0	0.0		
No	22.8	13.3	0.0	100.0		

Upper Back					4.156	0.245
Disorder Disorder					1.120	0.2 13
Yes	45.7	60.0	0.0	100.0		
No	54.3	40.0	100.0	0.0		
Low Back Disorder					1.015	0.798
Yes	22.8	26.7	0.0	0.0		
No	77.2	73.3	100.0	100.0		
Hip Disorder					2.281	0.516
Yes	72.8	86.7	100.0	50.0		
No	27.2	13.3	0.0	50.0		
Knee Disorder					2.855	0.415
Yes	57.6	73.3	0.0	50.0	2.000	01.10
No	42.4	26.7	100.0	50.0		
Ankle Disorder					2.127	0.546
Yes	71.7	60.0	100.0	100.0	,	- · - · •
No	28.3	40.0	0.0	0.0		

The above mentioned table represents the cross tabulation for presence of different types of Musculoskeletal disorders in the participants depending upon the number of their family members. It shows that among these nine types of MSDs only wrist/ hand disorders (0.049) showed significant association with the number of family members of the participants. But there was no association between the number of family members to the neck disorders (0.168), shoulder disorders (0.064), elbow disorders (0.769), upper back disorders (0.245), low back disorders (0.798), hip disorders (0.516), knee disorders (0.415) and ankle disorders (0.546).

Table 18. Cross Tabulation among the types of MSDs and Type of Present Illness (n=110)

Variables	Ту	Chi Square	P value			
Neck Disorder	Musculoskeletal	Neurological	Both	Absent	8.399	0.038
Yes	42.1	100.0	50.0	83.3		
No	57.9	0.0	50.0	16.7		
Shoulder Disorder					6.789	0.079
Yes	57.9	0.0	50.0	91.7		
No	42.1	100.0	50.0	8.3		
Elbow Disorder					2.863	0.413
Yes	73.7	100.0	100.0	91.7		
No	26.3	0.0	0.0	8.3		
Wrist/Hand Disorder					5.108	0.164
Yes	73.7	100.0	100.0	100.0		
No	26.3	0.0	0.0	0.0		
Upper Back Disorder					9.980	0.019
Yes	43.2	0.0	100.0	83.3		
No	56.8	100.0	0.0	16.7		
Low Back Disorder					29.693	0.000
Yes	14.7	0.0	50.0	83.3		
No	85.3	100.0	50.0	16.7		
Hip Disorder					5.931	0.115
Yes	70.5	100.0	100.0	100.0		
No	29.5	0.0	0.0	0.0		
Knee Disorder					9.277	0.026
Yes	55.8	100.0	0.0	91.7		
No	44.2	0.0	100.0	8.3		
Ankle Disorder					6.190	0.103
Yes	70.5	100.0	0.0	83.3		
No	29.5	0.0	100.0	16.7		

The above mentioned table represents the cross tabulation for presence of different types of Musculoskeletal disorders in the participants depending upon the type of present illness in the participants. It shows that among these nine types of MSDs, Low back disorders (0.000) has highly association with the type of present illness in the participants followed by Neck disorders (0.038), Wrist disorders (0.164), Upper back disorders (0.019), Knee disorders (0.026) and no association with Shoulder disorders (0.079), Elbow disorders (0.413), Hip disorders (0.115) and Ankle disorders (0.103).

Table 19. Cross Tabulation among the types of MSDs and Type of Chronic Illness (n=110)

Variables				Type of C	hronic Illness			Chi Squa	P Value
NII-	CVC	D	D1J	T C42	T61	N/1-4-112-	A 1	re	0.150
Neck Disorder	CVS	Resp	Blood	Infection	Inflammator 	Metabolic	Absen	9.276	0.159
Yes	22.2	167	20.0	0.0	y	22.2	t 53.1		
	33.3 66.7	16.7	30.0		100.0	33.3 66.7	33.1 46.9		
No	00.7	83.3	70.0	100.0	0.0	00.7	40.9		
Shoulder								9.689	0.138
Disorder								7.007	0.130
Yes	33.3	50.0	30.0	50.0	50.0	33.3	69.1		
No	66.7	50.0	70.0	50.0	50.0	66.7	30.9		
110	00.7	50.0	70.0	20.0	30.0	00.7	30.7		
Elbow								8.059	0.234
Disorder								0.000	
Yes	33.3	83.3	90.0	50.0	100.0	50.0	77.8		
No	66.7	16.7	10.0	50.0	0.0	50.0	22.2		
Wrist/Ha								3.140	0.791
nd									
Disorder									
Yes	100	83.3	70.0	50.0	50.0	83.3	77.8		
No	0.0	16.7	30.0	50.0	50.0	16.7	22.2		
Upper								3.370	0.761
Back									
Disorder									
Yes	33.3	50.0	40.0	50.0	0.0	33.3	51.9		
No	66.7	50.0	60.0	50.0	100.0	66.7	48.1		

Low Back Disorder Yes	0.0	16.7	0.0	0.0	50.0	0.0	28.4	8.631	0.195
No	100	83.3	100.0	100.0	50.0	100.0	71.6		
Hip Disorder Yes No	66.7 33.3	83.3 16.7	70.0 30.0	50.0 50.0	100.0 0.0	66.7 33.3	75.3 24.7	1.990	0.921
Knee Disorder Yes No	33.3 66.7	50.0 50.0	20.0 80.0	50.0 50.0	50.0 50.0	33.3 66.7	67.9 32.1	11.73 4	0.068
Ankle Disorder Yes No	66.7 33.3	83.3 16.7	60.0 40.0	0.0 100.0	100.0 0.0	50.0 50.0	74.1 25.9	8.413	0.209

The above mentioned table represents the cross tabulation for presence of different types of Musculoskeletal disorders in the participants depending upon the type of chronic illness in the participants. It shows that there is no association between these nine types of MSDs and type of chronic illness in the participants i,e. neck disorders (0.159), shoulder disorders (0.138), elbow disorders (0.234), wrist/ hand disorders (0.791), upper back disorders (0.761), low back disorders (0.195), hip disorders (0.921), knee disorders (0.068) and ankle disorders (0.209).

CHAPTER V DISCUSSION

The purpose of the study was to find out the presence of Musculoskeletal Disorders in Primary Caregivers of Children with Cerebral Palsy in CRP, Savar. This study was the first of its kind to find out the disorders related to musculoskeletal along with care giver stress index among the primary care givers of children with Cerebral palsy in Bangladesh. The study revealed that most of the primary care givers of children with Cerebral palsy were their mothers which show that likely to the Asian culture the children are primarily cared by the female members of their family who are mostly their mothers, grandmothers and aunties. The problems faced by the Cerebral palsy children and their primary caregivers are higher in context of Bangladeshi population as the diagnosis process is slow and also they lack required services here (Khandaker et al., 2018, p. 601-609). The participants were mostly Muslims (97%) and (3%) Hindus. Cerebral palsy is mostly prevalence in Muslim community due to genetic cause related to consanguineous marriage system (Bhatta, and Haque, 2014, p. 633-649). This study also showed that there are maximum numbers of Cerebral palsy children residing at rural part of (59%) than at semi urban part (16%) and urban part (25%) of the country.

The study found out that most of the children with cerebral palsy of the participants were among the age group of 2-6 years (77.3%) followed by 7-11 years (17.3%) and lastly 12-16 years (5.5%). Some conditions and disorders of the Cerebral palsy children may be seen after some age when they start going to school or later on as Cerebral palsy switches from condition to condition along the age of the child. The care of those children should be maintained from their childhood to the developing age till they become independent (Aneja, 2004, p. 627-634).

This study showed that maximum numbers of child with CP of the participants had Spastic (45.5%) type of CP followed by Flaccid (17.3%), Mixed (17.3), Athetoid (11.8), Hemiplegic (5.5%), Hypotonic (1.8) and Ataxic (0.9) type of CP.

This study, for Care giver Strain Index among the participants found out that there have been work adjustments e.g., because of having to take time off (88.2%) which is the highest number of the total followed by There have been changes in personal plans e.g., had to turn down a job; could not go on vacation (87.3%), Sleep is disturbed e.g., because is in and out of bed or wanders around at night (60%), There have been emotional adjustments e.g., because of severe arguments (57.3%), It is confining e.g., helping restricts free time or cannot go visiting (53.6%), It is upsetting to find has changed so much from his/her former self e.g., he/she is a different person than he/she used to be (50.9%), There have been family adjustments e.g., because helping has disrupted routine; there has been no privacy (38.2%) and It is a financial strain (38.2%), Some behavior is upsetting e.g., because of incontinence; has trouble remembering things; or accuses people of taking things (37.3%), It is inconvenient e.g., because helping takes so much time or it's a long drive over to help (26.4%). It is a physical strain e.g., because of lifting in and out of a chair; effort or concentration is required (16.4%) and Feeling completely overwhelmed e.g., because of worry about; concerns about how you will manage (14.5%). As mothers of children with cerebral palsy are considered to be their primary caregivers and spend most of the time with them should be provided with special training sessions in order to care the children. These mothers are mostly affected physically and psychologically themselves. (Nobakht, Rassafiani, Hosseini, & Hosseinzadeh, 2020). Out of total score of 12 for CSI, 53 out of 110 participants got the score equals to and more than 7 which indicates a need for intervention in the particular area.

This study concluded that the age of child is positively correlated to the age of their primary care givers (0.001) whereas it is not correlated to the marital status (0.650), education level (0.377), occupation (0.540) and relationship (0.619) of the primary care givers. The study showed no correlation between the type of cerebral palsy to the age (0.839), marital status (0.319), education level (0.380), occupation (0.197), relationship (0.149) and home area (0.382) of the primary care givers.

This study revealed that there is positive correlation between the weight of the child to the age (0.22) of their primary care givers but no correlation between their weight and marital status (0.643), education level (0.979), occupation (0.469), relationship (0.227) and home area (0.077) of the primary caregivers.

The study also found highly positive correlation between the use of assistive devices by the cerebral palsy children to the home area (0.000) of their primary care givers where as no significant correlation between the use of assistive devices by them to the age (0.170), marital status (0.664), education level (0.243), occupation (0.431) and relationship (0.083) of their primary care givers. (Eker & Tüzün, 2004) concluded that the lifestyle of the mothers as primary caregivers of children with cerebral palsy face more problems for dealing with the provided care and also have a different psychosocial life than that of the children with other health issues.

A chi-square analysis was conducted with p<.05 to find out the significant association between presence of different types of Musculoskeletal disorders in the participants depending upon their home area. Within the nine types of musculoskeletal disorders divided according to the site of disorders only neck disorders (0.023), knee disorders (0.014) and ankle disorders (0.018) had significant association with the home area they reside. But no significant association between shoulder disorders (0.336), elbow disorders (0.270), wrist/hand disorders (0.099), upper back disorders (0.512), low back disorders (0.317) and hip disorders (0.144) and the home area the participants reside at. The people living in the rural part of Bangladesh are found to have more possibility of musculoskeletal pain as well as rheumatic diseases. Low back pain, knee pain and muscular rheumatism are usually occurring disorders among them (HAQ et al., 2008, p. 216-223).

This study also showed that 86.4% of the children with CP were under the weight range of 5-20 kgs whereas 10% were under 21-36 kgs and other 3.6% were under 37-52 kgs respectively.

This study conducted another chi-square analysis with p<.05 to show the significant association between presence of different types of Musculoskeletal disorders in the participants depending upon the weight of their respective CP children. Within those nine types of musculoskeletal disorders only knee disorders had the significant association with the weight of the respective child which is 0.036. Whereas, there was no association between the neck disorders (0.375), shoulder disorders (0.058), elbow disorders (0.418), wrist/ hand disorders (0.398), upper back disorders (0.413), low back disorders (0.523), hip disorders (0.275) and ankle disorders (0.093) with the weight of the respective CP child. (Tarsuslu Simsek & Tuc, 2014) supported that the common causes of the low weight in the children with CP were lack of proper diet, lack of muscular functions, developmental delay and lack of proper health care by the care givers.

This study also revealed that most of the children with cerebral palsy do not use assistive devices (66.4%) and others 33.6% of them use the assistive devices. Among the assistive devices most of them used orthotic devices (14.5%), followed by chair/ seat (10%), frames (6.4%) and back slab (2.7%). Another chi-square analysis with p<.05 was conducted to show the significant association between presence of different types of Musculoskeletal disorders in the participants and assistive devices used by their respective CP child. Within those nine types of MSDs divided according to the site of disorders as neck disorders (0.238), shoulder disorders (0.124), elbow disorders (0.890), wrist/ hand disorders (0.741), upper back disorders (0.393), low back disorders (0.236), hip disorders (0.062), knee disorders (0.266) and ankle disorders (0.263) there is no significant association between these MSDs and assistive devices used by the CP child. (Henderson, Skelton, & Rosenbaum, 2008) suggested that the type of assistive devices used by the CP children depending upon their physical inability plays a significant role in making their ADLs easier and comfortable as mentioned by the ICF as well. The use of devices might also help to benefit the children's caregivers, family as well as the society.

Another chi-square analysis with p<.05 was also conducted to find out the significant association between presence of different types of Musculoskeletal disorders in the participants and number of family members in their respective family. Among these nine types of MSDs only wrist/ hand disorders (0.049) showed significant association with the number of family members of the participants. But there was no association between the number of family members to the neck disorders (0.168), shoulder disorders (0.064), elbow disorders (0.769), upper back disorders (0.245), low back disorders (0.798), hip disorders (0.516), knee disorders (0.415) and ankle disorders (0.546). This study also showed that among the types of Musculoskeletal disorders most of the participants had wrist/ hand disorders (77.3%), also elbow disorders (76.4%), followed by hip disorders (74.5%), ankle disorders (70.9%), shoulder disorders (60.9%), knee disorders (59.1%), upper back disorders (48.2%), neck disorders (47.3%) and low back disorders (22.7%). As contrast to this study, (Czupryna, Nowotny-Czupryna, & Nowotny, 2014, p. 497-505) contradicted that due to continuous supervision of the cerebral palsy children their mothers as primary caregivers mostly tend to develop back pain. The quality of this back pain totally depends on the bodily growth and functional ability of the child.

5.1 Limitation of the study

There were some factors limiting the findings of the study. They are:

- 1. The sample size was small.
- 2. There was no comparison group for the participants.
- 3. The researcher was not fluent in Bangla language speaking and understanding so it was quite difficult communicating to the participants.
- 4. The study period was limited.
- 5. Lack of similar researches on the similar topics.
- 6. The research was conducted inside only one institute which made the results of the study unable to be generalized.

CHAPTER VI

Chapter 6.1 Conclusion:

This study concluded that the primary caregivers of the CP children are female members mostly the mothers. The participants were mostly Muslims and from consanguineous marriage culture. There were maximum numbers of cerebral palsy children residing at rural part of the country. Only neck disorders (0.023), knee disorders (0.014) and ankle disorders (0.018) had significant association with the home area they reside. Most of these caregivers were found to have wrist/ hand disorders (77.3%), also elbow disorders (76.4%), followed by hip disorders (74.5%), ankle disorders (70.9%), shoulder disorders (60.9%), knee disorders (59.1%), upper back disorders (48.2%), neck disorders (47.3%) and low back disorders (22.7%) respectively among the types of Musculoskeletal disorders named according to the site of pain or disorders namely; Neck disorders, Shoulder disorders, Elbow disorders, Wrist/ hand disorders, Upper back disorders, Low back disorders, Hip disorders, Knee disorders and Ankle disorders.

For Care giver Strain Index among the maximum participants it was found to be that there have been work adjustments e.g., because of having to take time off.

Most of the primary caregivers of the children with Cerebral palsy who were found to be their mothers are at high risk of developing musculoskeletal disorders followed by the care and services provided to those children. Hence, it is the high time for the health workers to work accordingly to manage and prevent this matter. Physiotherapy treatment protocols and awareness programs could be implemented in order to provide required services and knowledge about Cerebral palsy and its related musculoskeletal disorders in their primary caregivers.

6.2 Recommendations:

- 1. More number of samples could be taken and studied.
- 2. The quality of life of the primary care givers of CP children should also be evaluated.
- 3. Prevention, intervention and outcome regarding musculoskeletal symptoms should be considered for future studies.
- 4. As there was a scarcity of availability of similar researches, the study should not be limited to one institute rather it should be conducted in a large scale in Bangladesh.
- 5. Depression and other psychological issues related to the lifestyle of the study population regarding having a CP child should also be evaluated in Bangladesh.

CHAPTER VII REFERENCES

Aneja, S. (2004). Evaluation of a child with cerebral palsy. *The Indian Journal of Pediatrics*, 71(7), 627-634. https://doi.org/10.1007/bf02724123

- Barks, L. (2004). Therapeutic positioning, wheelchair seating, and pulmonary function of children with cerebral palsy: A research synthesis. *Rehabilitation Nursing*, 29(5), 146-153. https://doi.org/10.1002/j.2048-7940.2004.tb00337.x
- Bernard, B. P. (1997). Musculoskeletal disorders and workplace factors. A critical review of epidemiologic evidence for work-related musculoskeletal disorders of the neck, upper extremity, and low back. https://doi.org/10.26616/nioshpub97141
- Bhatta, D. N., & Haque, A. (2014). Health problems, complex life, and consanguinity among ethnic minority Muslim women in Nepal. *Ethnicity & Health*, 20(6), 633-649. https://doi.org/10.1080/13557858.2014.980779
- Brehaut, J. C., Kohen, D. E., Raina, P., Walter, S. D., Russell, D. J., Swinton, M., & Rosenbaum, P. (2004). The health of primary caregivers of children with cerebral palsy: How does it compare with that of other Canadian caregivers?

 *PEDIATRICS, 114(2), e182-e191. https://doi.org/10.1542/peds.114.2.e182
- Byrne, M. B., Hurley, D. A., Daly, L., & Cunningham, C. G. (2010). Health status of caregivers of children with cerebral palsy. *Child: Care, Health and Development*, 36(5), 696-702. https://doi.org/10.1111/j.1365-2214.2009.01047.x
- Czupryna, K., Nowotny-Czupryna, O., & Nowotny, J. (2014). Back pain in mothers of cerebral palsied children. *Ortopedia Traumatologia Rehabilitacja*, *16*(5), 497-505. https://doi.org/10.5604/15093492.1128840

- Davis, E., Shelly, A., Waters, E., Boyd, R., Cook, K., & Davern, M. (2010). The impact of caring for a child with cerebral palsy: Quality of life for mothers and fathers. *Child: Care, Health and Development*, *36*(1), 63-73. https://doi.org/10.1111/j.1365-2214.2009.00989.x
- Eker, L., & Tüzün, E. H. (2004). An evaluation of quality of life of mothers of children with cerebral palsy. *Disability and Rehabilitation*, 26(23), 1354-1359. https://doi.org/10.1080/09638280400000187
- Garip, Y., Ozel, S., Tuncer, O. B., Kilinc, G., Seckin, F., & Arasil, T. (2016). Fatigue in the mothers of children with cerebral palsy. *Disability and Rehabilitation*, *39*(8), 757-762. https://doi.org/10.3109/09638288.2016.1161837
- Gopichandran, V., Vadivelan, K., Sekar, P., & Sru, S. S. (2020). Burden of caregivers of children with cerebral palsy: An intersectional analysis of gender, poverty, stigma, and public policy. https://doi.org/10.21203/rs.3.rs-16838/v1
- Habib, R. R., Fathallah, F. A., & Messing, K. (2010). Full-time homemakers: Workers who cannot "Go home and relax". International Journal of Occupational Safety and Ergonomics, 16(1), 113-128.
 https://doi.org/10.1080/10803548.2010.11076833
- Haq, S. A., Darmawan, J., Islam, M. N., Uddin, M. Z., Das, B. B., Rahman, F.,
 Chowdhury, M. A., Alam, M. N., Mahmud, T. A., Chowdhury, M. R., & Tahir,
 M. (2005). Prevalence of rheumatic diseases and associated outcomes in rural and urban communities in Bangladesh: a COPCORD study. National library of medicine, 32234853, 348-53.

- HAQ, S. A., DARMAWAN, J., ISLAM, M. N., AHMED, M., BANIK, S. K., Fazlur Rahman, A. K., & RASKER, J. J. (2008). Incidence of musculoskeletal pain and rheumatic disorders in a Bangladeshi rural community: A WHO-APLAR-COPCORD study. *International Journal of Rheumatic Diseases*, 11(3), 216-223. https://doi.org/10.1111/j.1756-185x.2008.00364.x
- Henderson, S., Skelton, H., & Rosenbaum, P. (2008). Assistive devices for children with functional impairments: Impact on child and caregiver function. *Developmental Medicine & Child Neurology*, 50(2), 89-98. https://doi.org/10.1111/j.1469-8749.2007.02021.x
- Kaya, K., Unsal-Delialioglu, S., Ordu-Gokkaya, N. K., Ozisler, Z., Ergun, N., Ozel, S., & Ucan, H. (2010). Musculo-skeletal pain, quality of life and depression in mothers of children with cerebral palsy. *Disability and Rehabilitation*, 32(20), 1666-1672. https://doi.org/10.3109/09638281003649912
- Khandaker, G., Muhit, M., Karim, T., Smithers-Sheedy, H., Novak, I., Jones, C., & Badawi, N. (2018). Epidemiology of cerebral palsy in Bangladesh: A population-based surveillance study. *Developmental Medicine & Child Neurology*, 61(5), 601-609. https://doi.org/10.1111/dmcn.14013
- Krstic, T., & Oros, M. (2012). Coping with stress and adaptation in mothers of children with cerebral palsy. *Medical review*, 65(9-10), 373-377. https://doi.org/10.2298/mpns1210373k
- Mobarak, R., Khan, N. Z., Munir, S., Zaman, S. S., & McConachie, H. (2000). Predictors of stress in mothers of children with cerebral palsy in Bangladesh. *Journal of Pediatric Psychology*, 25(6), 427-433. https://doi.org/10.1093/jpepsy/25.6.427

- Muñoz-Marrón, E., Redolar, D., Boixadós, M., Nieto, R., Guillamón, N., Hernández, E., & Gómez, B. (2013). undefined. *Universitas Psychologica*, 12(3). https://doi.org/10.11144/javeriana.upsy12-3.bccc
- National Institute for occupational safety and health. (1997). https://doi.org/10.26616/nioshpub97121
- Neves, E. B., Pietrovski, E. F., & Claudino, R. F. (2015). Quality of life and low back pain in primary caregivers of children with cerebral palsy. *Cadernos Saúde Coletiva*, 23(1), 50-56. https://doi.org/10.1590/1414-462x201500010009
- Nobakht, Z., Rassafiani, M., Hosseini, S., & Hosseinzadeh, S. (2020). A web-based daily care training to improve the quality of life of mothers of children with cerebral palsy: A randomized controlled trial. *Research in Developmental Disabilities*, 105, 103731. https://doi.org/10.1016/j.ridd.2020.103731
- Ones, K., Yilmaz, E., Cetinkaya, B., & Caglar, N. (2005). Assessment of the quality of life of mothers of children with cerebral palsy (Primary caregivers). Neurorehabilitation and Neural Repair, 19(3), 232-237. https://doi.org/10.1177/1545968305278857
- Ortiz-Hernández, L., Tamez-González, S., Martínez-Alcántara, S., & Méndez-Ramírez, I. (2003). Computer use increases the risk of musculoskeletal disorders among newspaper office workers. *Archives of Medical Research*, *34*(4), 331-342. https://doi.org/10.1016/s0188-4409(03)00053-5
- Prakash, V., Patel, A. M., Hariohm, K., & Palisano, R. J. (2016). Higher levels of caregiver strain perceived by Indian mothers of children and young adults with

- cerebral palsy who have limited self-mobility. *Physical & Occupational Therapy In Pediatrics*, *37*(1), 64-73. https://doi.org/10.3109/01942638.2015.1138016
- Raina, P., O'Donnell, M., Schwellnus, H., Rosenbaum, P., King, G., Brehaut, J., & Wood, E. (2004). Caregiving process and caregiver burden: Conceptual models to guide research and practice. *BMC Pediatrics*, *4*(1). https://doi.org/10.1186/1471-2431-4-1
- Rentinck, I. C., Ketelaar, M., Jongmans, M. J., & Gorter, J. W. (2007). Parents of children with cerebral palsy: A review of factors related to the process of adaptation. *Child: Care, Health and Development*, *33*(2), 161-169. https://doi.org/10.1111/j.1365-2214.2006.00643.x
- Rigby, P., Reid, D., Schoger, S., & Ryan, S. (2001). Effects of a wheelchair-mounted rigid pelvic stabilizer on caregiver assistance for children with cerebral palsy.

 Assistive Technology, 13(1), 2-11.

 https://doi.org/10.1080/10400435.2001.10132029
- Sharan, D., Ajeesh, P., Rameshkumar, R., & Manjula, M. (2012). Musculoskeletal disorders in caregivers of children with cerebral palsy following a multilevel surgery. *Work*, *41*, 1891-1895. https://doi.org/10.3233/wor-2012-0403-1891
- Stringfellow, A. (n.d.). *What is a primary caregiver?*. https://www.seniorlink.com/blog/what-is-a-primary-caregiver
- Tarsuslu Simsek, T., & Tuc, G. (2014). Examination of the relation between body mass index, functional level and health-related quality of life in children with cerebral palsy. *Türk Pediatri Arşivi*, 49(2), 130-137. https://doi.org/10.5152/tpa.2014.1238

- TERZI, R., & Tan, G. (2015). Musculoskeletal system pain and related factors in mothers of children with cerebral palsy. *Ağrı The Journal of The Turkish Society of Algology*. https://doi.org/10.5505/agri.2015.74436
- Waters, E., Maher, E., Salmon, L., Reddihough, D., & Boyd, R. (2005). Development of a condition-specific measure of quality of life for children with cerebral palsy:

 Empirical thematic data reported by parents and children. *Child: Care, Health and Development*, 31(2), 127-135. https://doi.org/10.1111/j.1365-2214.2004.00476.x
- Wu, J., Zhang, J., & Hong, Y. (2017). Quality of life of primary caregivers of children with cerebral palsy: A comparison between mother and grandmother caregivers in Anhui province of China. *Child: Care, Health and Development*, 43(5), 718-724. https://doi.org/10.1111/cch.12464

APPENDIX

I. Approval of Thesis Proposal by Ethics Committee of BHPI:



বাংলাদেশ হেল্থ প্রফেশন্স ইনস্টিটিউট (বিএইচপিআই) Bangladesh Health Professions Institute (BHPI)

(The Academic Institute of CRP)

Ref.

CRP-BHPI/IRB/08/19/1315

Date: 20/08/2019

Neha Regmi M.Sc. in Rehabilitation Science (MRS) Session: 2018-2019, Student ID 181180116 BHPI, CRP-Savar, Dhaka-1343, Bangladesh

Subject: Approval of thesis proposal "Musculoskeletal Disorders in Primary Caregivers of Children with Cerebral Palsy in CRP" by ethics committee.

Dear Neha Regmi,

Congratulations,

The Institutional Review Board (IRB) of BHPI has reviewed and discussed your application to conduct the above mentioned thesis, with yourself, as the Principal Investigator" The Following documents have been reviewed and approved:

S.N.	Name of Documents
1.	Thesis Proposal
2.	Questionnaire (Bangla version)
3.	Information sheet & consent form.

Since the study involves use of a "Nordic Questionnaire" and "Care Giver Stress Index" to identify the Musculoskeletal Disorders in Primary Caregivers of Children with Cerebral Palsy in CRP that may take 15 to 20 minutes to fill in the questionnaire for collection of data. Since, there is no likelihood of any harm to the participants in the study; the members of the Ethics Committee have approved the study to be conducted in the presented form at the meeting held at 3.00 pm on 17 February, 2019 at BHPI.

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

Best regards,

Willathansaer

Muhammad Millat Hossain

Assistant Professor, Dept. of Rehabilitation Science

Member Secretary, Institutional Review Board (IRB)

BHPI, CRP, Savar, Dhaka-1343, Bangladesh

সিআরপি-চাপাইন, সাভার, ঢাকা-১৩৪৩, বাংলাদেশ, ফোন ঃ ৭৭৪৫৪৬৪-৫, ৭৭৪১৪০৪ ফ্যাক্স ঃ ৭৭৪৫০৬৯

CRP-Chapain, Savar, Dhaka-1343, Tel: 7745464-5, 7741404, Fax: 7745069, E-mail: contact@crp-bangladesh.org, www.crp-bangladesh.org

II. Recommendation letter from BHPI:

To,
The Chairman
Institutional Review Board (IRB)
Bangladesh Health Professions Institute (BHPI)
CRP-Savar, Dhaka-1343, Bangladesh
Subject: Application for review and ethical approval

Sir,

With due respect I would like to draw your kind attention that I am a student of M.Sc. in Rehabilitation Science program at Bangladesh Health Professions Institute (BHPI)- an academic institute of CRP under Faculty of Medicine, University of Dhaka (DU). This is a 2-year full-time course under the project of "Regional Inter-Professional Masters program in Rehabilitation Science" funded by SAARC Development Fund (SDF). I have to conduct a thesis entitled, "Musculoskeletal Disorders in Primary Caregivers of Children with Cerebral Palsy in CRP", under the honorable supervisor, Dr. Kamal Ahmed, Former Associate Professor, IHT, Mohakhali. The purpose of the study is to find out the presence and types of musculoskeletal disorders in primary caregivers of children with cerebral palsy.

Date: 19/08/2019

The study involves use of Nordic musculoskeletal questionnaire and Caregiver Strain Index (CSI) for determining the presence and types of musculoskeletal disorders and that may take 15-20 minutes to fill in the questionnaire. There is no likelihood of any harm to the participants and for participation in the study may benefit the participants or other stakeholders. Related information will be collected from the participants. Data collectors will receive informed consent from all participants. Any data collected will be kept confidential.

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

Sincerely, Neha Regmi

MRS 5thBatch

Student of M.Sc. in Rehabilitation Science (MRS) BHPI, CRP, Savar, Dhaka-1343, Bangladesh

Recommendation from the thesis supervisor:

Dr. Kamal Ahmed,

Former Associate Professor, IHT, Mohakhali

Attachment: Thesis Proposal including measurement tools and process and procedure for maintaining confidentiality, Questionnaire (English and Bengali version), Information sheet& consent

III. Permission letter for Data Collection from William Marie Taylor School, CRP:

Date: 20/08/2019

To, Acting The Vice-Principal

William and Marie Taylor School

CRP, Chapain, Savar, Dhaka-1343

Subject: Application for the permission of data collection for research purpose

Respected sir.

With due respect and humble request I would like to draw your kind attention that I am Neha Regmi, student of Msc. In Rehabilitation Science program at Bangladesh Health Professions Institute (BHPI)- an academic institution of CRP under Faculty of Medicine of university of Dhaka (DU). As I am studying under the two-year full time course under the project of "Regional Inter- Professional Master's Program in Rehabilitation Science" funded by SAARC Development Fund (SDF) and per the approval by the ethical review committee of BHPI, I have to conduct a thesis entitled "Musculoskeletal Disorders in Primary Caregivers of Children with Cerebral Palsy in CRP" under supervision of honorable supervisor Dr. Kamal Ahmed, Former Associate Professor, IHT, Mohakhali.

The purpose of my study is to find out the presence and types of musculoskeletal disorders in primary caregivers of the cerebral palsy children. This research will surely help in creating awareness to the primary caregivers of the cerebral palsy children about the risk factors of musculoskeletal disorders. Well structured questionnaire will be used to collect data by the data collector from the participants and it will take about 15-20 minutes. The collected data will be kept very confidential and the procedure will cause any harm to the participants.

I therefore, hope that you would be kind enough to accept my application and grant me permission to collect data to accomplish my research and thesis work.

Thanking you.

Yours sincerely,

Neha Regmi

MRS 5th Batch

BHPI, CRP, Chapain, Savar, Dhaka-1343

Perconitted.

IV. Permission letter from In Charge of Pediatric Unit, CRP:

Date 20 08 2019

To.

The Incharge of Pediatric Unit / Head of the Dept.

CRP, Chapain, Savar, Dhaka-1343

Subject: Application for the permission of data collection for research purpose

Respected sir/madam,

With due respect and humble request I would like to draw your kind attention that I am Neha Regmi, student of Msc. In Rehabilitation Science program at Bangladesh Health Professions Institute (BHPI)- an academic institution of CRP under Faculty of Medicine of university of Dhaka (DU). As I am studying under the two-year full time course under the project of "Regional Inter- Professional Master's Program in Rehabilitation Science" funded by SAARC Development Fund (SDF) and per the approval by the ethical review committee of BHPI, I have to conduct a thesis entitled "Musculoskeletal Disorders in Primary Caregivers of Children with Cerebral Palsy in CRP" under supervision of honorable supervisor Dr. Kamal Ahmed, Former Associate Professor, IHT, Mohakhali.

The purpose of my study is to find out the presence and types of musculoskeletal disorders in primary caregivers of the cerebral palsy children. This research will surely help in creating awareness to the primary caregivers of the cerebral palsy children about the risk factors of musculoskeletal disorders. Well structured questionnaire will be used to collect data by the data collector from the participants and it will take about 15-20 minutes. The collected data will be kept very confidential and the procedure will cause any harm to the participants.

I therefore, hope that you would be kind enough to accept my application and grant me permission to collect data to accomplish my research and thesis work.

Thanking you.

Yours sincerely,

Neha Regmi

MRS 5th Batch

BHPI, CRP, Chapain, Savar, Dhaka-1343

She will will collect last of plane help

PARE STATE OF

V. INFORMATION SHEET (English):

Hello,

I am Neha Regmi, student of the Bangladesh Health Professions Institute (BHPI) which is the academic institute of the Centre for the Rehabilitation of the Paralyzed (CRP), Savar, Dhaka. I am studying M.Sc. in Rehabilitation. In regards to the fulfillment of M.Sc. Degree, it is mandatory to conduct a research in final year of study. I request you to participate in this research study "Title: Musculoskeletal Disorders in Primary Caregivers of Children with Cerebral Palsy in CRP". It will be very helpful if you accept my invitation and take part in my study.

If you agree to participate in this study, you will be asked a certain question regarding the socio-demographic data regarding age, weight and condition of your child. For other part of the study, you will be asked few questions regarding the difficulties faced by you while taking care of the child. This will take approximately 15-20 minutes and you can voluntarily participate in this study.

The purpose of my study is to find out the presence and types of musculoskeletal disorders in you. This study will surely help in creating awareness to you and will be very helpful. Please try to give truthful answer as much as possible and you can also refuse to give answer if you are

not comfortable at sharing the information. If you have any questions regarding the questionnaire, you can ask it anytime. All the information provided by you will be kept very confidential. The identity of your will not be disclosed in any presentation or publication without your agreement. If you have any queries now regarding this study please feel free to ask. I am accountable to answer all questions regarding this study. Neha Regmi

M. Sc. in Rehabilitation Science, BHPI, CRP, Savar, Dhaka.

Participant's signature:	Date:
Investigator's signature:	Date:

VI. INFORMATION SHEET (Bangla):

আসসালামু আলাইকুম,

আমি নেহা রেগমী, পক্ষাঘাতগ্রস্তদেরপুনর্বাসনকেন্দ্রএরএকাডেমিকইনস্টিটিউট (সিআরপি), বাংলাদেশ হেলথ প্রফেশনস ইনস্টিটিউট (বিএইচপিআই) এর এম.এস.সি ইন রিহ্যাবিলিটেশন কোর্সের একজন ছাত্রী। এম.এস.সি ডিগ্রী অর্জন করার জন্য আমাকে বাধ্যতামূলক একটি গবেষণা সম্পাদন করতে হবে। আমার রিসার্চের বিষয়ঃ সিআরপিতে সেরেব্রাল পালসি আক্রান্ত বাচ্চাদের প্রাথমিক রক্ষণাবেক্ষনকারীদের মাংসপেশিজনিত অসুস্থতা। আমি আপনাকে এই গবেষণায় অংশগ্রহণ করার জন্য আমন্ত্রণ জানাচ্ছি। আপনি যদি আমার গবেষণায় অংশ নিতে রাজি থাকেন তাহলে আপনাকে সামাজিক প্রেক্ষাপটের তথ্যাবলি সংক্রান্ত কিছু প্রশ্ন করা হবে, যেমনঃ আপনার বাচ্চার বয়স, ওজন এবং অবস্থা। গবেষণার অন্যান্য অংশ বাচ্চার যত্ন নেয়ার সময় আপনি কী ধরণের সমস্যার সম্মুখীন হন সে বিষয়ে প্রশ্ন করা হবে। এজন্য ১৫-২০ মিনিট সময় প্রয়োজন হবে এবং আপনি স্বেছায় এই গবেষণায় অংশগ্রহণ করতে পারেন।

আমার গবেষণার মূল লক্ষ্য হচ্ছে, আপনার মধ্যে মাংশপেশিজনিত কোনো সমস্যা আছে কী না এবং যদি থাকে তাহলে তার ধরণ নির্ণয় করা। এই গবেষণা আপনার মধ্যে সচেতনতা তৈরি করতে সাহায্য করবে। অনুগ্রহ করে প্রশ্নগুলোর যথাসম্ভব নির্ভুল উত্তর দেয়ার চেষ্টা করবেন। আপনি কাছে অস্বস্তিকর মনে হওয়া প্রশ্নগুলো চাইলে আপনি এড়িয়ে যেতে পারবেন। প্রশ্নপত্র নিয়ে যদি কোনো জিজ্ঞাসা থাকে সেটি যেকোনো সময় আপনি জেনে নিতে পারবেন। আপনার ব্যক্তিগত তথ্য সম্পূর্ণভাবে গোপনীয় থাকবে এবং ভবিষ্যতে আপনার অনুমতি ছাড়া কোথাও এগুলো প্রকাশ করা হবে না। যদি এই গবেষণা নিয়ে আপনার আর কিছু জানার থাকে তাহলে আপনি এখনি জিজ্ঞেস করতে পারেন। আমি এই গবেষণা সংক্রান্ত যেকোনো তথ্য আপনাকে দিতে প্রস্তুত আছি।

নেহা রেগমী

এম এস সি ইন রিহ্যাবিলিটেশন সাইন্স, বিএইচপিআই, সিআরপি, সাভার, ঢাকা।

অংশগ্রহণকারীর স্বাক্ষরঃ তারিখঃ

তথ্য সংগ্রহকারীর স্বাক্ষরঃ তারিখঃ

VII. CONSENT FORM (English):

Please read the following statements and put tick ($\sqrt{}$) on yes or no to say that you understand

the content of the information sheet, your involvement, and that you agree to take part in the above-named study.

In giving my consent, I acknowledge that:

1. I have read the Information Statement and the time involved for my participation in the project. The researcher/s has given me the opportunity to discuss the information and

ask any questions, I have about the study and they have been answered to my satisfaction.

- 2. I understand that I can withdraw from the study at any time without prejudice to my or my child's relationship with the researcher/s now or in the future.
- 3. I understand that withdrawal from the study will not affect my relationship with receiving services from CRP or in the future.
- 4. I agree that research data gathered from the results of the study may be published provided that neither my child nor I can be identified.
- 5. I understand that if I have any questions relating to mine and my child's participation in this research I may contact the researcher/s who will be happy to answer them.
- 6. I acknowledge receipt of the Information Statement.
- 7. I agree to take part in the above study.

Signature of the Participant	
	Date
Investigator	
I have explained the study to the above	ve participant precisely and he/she has indicated a
willingness to take part.	
Investigator's signature	Date

VIII. CONSENT FORM (Bangla):

নিচেরবিবৃতিগুলোপড়ুনএবং তথ্যাবলি অনুধাবন, আপনার সংযুক্তি এবং আপনি যে উপরে বর্ণিত গবেষণাতে সাহায্য করতে আগ্রহী তা জানানোর জন্য হ্যাঁঅথবানাচিহ্নিতঘরেটিক (১৮৮৮) চিহ্ন দিন

আমি সজ্ঞানে সম্মতি দিচ্ছি যে.

- ১। আমি তথ্যাবলী এবং এই কাজে অংশগ্রহণের জন্য কতটুকু সময় প্রয়োজন তা পড়েছি। গবেষক আমাকে তথ্যাবলী এবং যেকোনো প্রশ্ন নিয়ে আলোচনা করার সুযোগ দিয়েছেন। আমি গবেষণা টি সম্পর্কে জ্ঞাত এবং তাদের উত্তরগুলো সন্তোষজনক ছিল।
- ২। আমি বুঝতে পেরেছি যে, বর্তমান বা ভবিষ্যতে গবেষকের সাথে আমার বা আমার বাচ্চার সুসম্পর্ক বজায় রাখতে আমি যেকোনো সময় গবেষণায় কাজ করা বন্ধ করতে পারি। ৩। আমি বুঝতে পেরেছি যে এই গবেষণাটির প্রত্যাহার বর্তমান বা ভবিষ্যতে সিআরপির সেবা গ্রহণে কোনো অন্তরায় হবে না।
- ৪। আমি বা আমার বাচ্চার পরিচয় উল্লেখ না করে গবেষণায় প্রয়োজনীয় যেকোনো তথ্য বা তার ফলাফল গবেষণায় প্রকাশ করতে আমি সম্মতি দিচ্ছি।
- ৫। আমি বুঝতে পারছি যে আমি বা আমার বাচ্চার এই গবেষণা অংশগ্রহণ সংক্রান্ত যেকোনো প্রশ্নের জন্য আমি গবেষকের সাথে যোগাযোগ করতে পারবো
- ৬। আমি তথ্যাবলীর একটি কপি বুঝে পেয়েছি।
- ৭। আমি উপরের গবেষণায় অংশ নিতে আগ্রহী।

অংশগ্রহণকারীর স্বাক্ষরঃ তারিখঃ

পরিদর্শক

আমি সম্পূর্ণ গবেষণাটি তাকে বিস্তারিতভাবে বর্ণনা করেছি এবং তিনি অংশগ্রহণের জন্য সম্মতি জ্ঞাপন করেছেন।

পরিদর্শকের স্বাক্ষরঃ তারিখঃ

IX. QUESTIONNAIRES:

SOCIO DEMOGRAPHIC INFORMATION QUESTIONS (English)

1. Age: □46-50years	□16-2	20years □21-25years □26-30years □31-35years □36-40years □41-45years
	2.	Gender: ☐ Male ☐ Female
	3. Separa	Marital status: ☐ Married ☐Unmarried ☐Divorced ☐ Widowed ☐
	4.	Education: \Box Illiterate \Box upto Class V \Box Upto Class VIII \Box Upto Class X \Box HSC \Box Bachelor \Box Masters or Above \Box N/A
	5. □ Farr	Occupation: \square House Wife \square Service Holder \square Business \square Day Laborer mer \square N/A \square Student
	6.	Religion: □ Muslim □ Hindu □ Christian
	7. □ Aun	Relationship with the child: □Mother/Father □Grandmother/Grandfather ty/Uncle □Siblings □ Aaya
	8.	Age of the child: □2-6years □7-11years □12-16years
	9.	Weight of the child: □5-20kgs □21-36kgs □37-52kgs
	10. □Fran	Does the child use any assistive devices: □Chair/Seat □Orthotic devices nes □ Back slab □Do not use
	11.	Type of CP motor type of the child: □ Spastic □ Flaccid □ Ataxic □ oid

□ Dystonic □ Hypotonic □ Unknown □ Mixed □ Hemiplegic
12. Home area: ☐ Urban ☐ Semi-Urban ☐ Rural
13. Monthly Family Income: □1000-10000 □11000-20000 □21000-30000 □31000-40000 □41000-50000 □51000-60000
14. Number of Family Members: □3-6 □7-10 □11-14 □15-18 □19-22
Medical history
15. Present illness: ☐ Musculoskeletal ☐Neurological ☐Absent
□Musculoskeletal+ Neurological
16. Duration: Past medical history: □Acute(in days) □Subacute (in months) □Chronic (in years)
17. Do you have any chronic illness? □Cardiovascular □Respiratory □Blood
□Infectious □Inflammatory □Injuries and Accidents □Metabolic and Endocrine
□Absent

SOCIO DEMOGRAPHIC INFORMATION QUESTIONS (Bangla)

প্রশ্নাবলী (সামাজিক প্রেক্ষাপটের তথ্যাবলী)

5। नामঃ
২। বয়সঃ
৩। লিঙ্গঃ 🗆 পুরুষ 🗀 নারী 🗀 অন্যান্য
81 বৈবাহিক অবস্থাঃ
৯। বাচ্চার বয়সঃ ১০। বাচ্চার ওজনঃ ১১। বাচ্চা কি কোনো সহায়ক যন্ত্র ব্যবহার করে? □ হাাঁ(উল্লেখ করুন)····· □ না
১২বাচ্চার সেরেব্রাল পালসি আক্রান্তের ধরণ 🔲 স্পাসটিক 🗆 ফ্ল্যাসিড 🗀 এটাক্সিক 🗀 এথেটয়েড ভিসটনিক 🗆 হাইপোটনিক 🗀 অজানা 🗆 মিশ্র
১৩। বসবাসের এলাকাঃ 🗆 শহর 🔲 উপশহর 🗀 গ্রাম ১৪। পরিবারের মাসিক জায়ঃ ১৫। পরিবারের সদস্য সংখ্যাঃ
চিকিৎসা সংক্রান্ত বিবরণ
১৬। বর্তমান সমস্যাঃ মাসকুলোম্বেলেটাল নিউরোলজিক্যাল ১৭। সময়কালঃ পূর্ববর্তী চিকিৎসার বিবরণ
১৮। আপনার কি দীর্ঘকালীন কোনো রোগ আছে? □ উচ্চ রক্তচাপ □ ডায়াবেটিস □ থাইরয়েডজনিত সমস্যা □ এজমা □ হৃদরোগ

NORDIC MUSCULOSKELETAL QUESTIONNAIRE (English):

Please answer by using the tick boxes - one tick for each question Please note that this part of the quest f you have never had trouble in any p	ionnaire should be answered, ev	
Have you at any time during the last 12 months had trouble (such as ache, pain, discomfort, numbness) in:	Have you had trouble during the last 7 days:	During the last 12 months have you been prevented from carrying out normal activities (eg. job, housework, hobbies) because of this trouble:
1 Neck	2 Neck No Yes 1 2	3 Neck No Yes
4 Shoulders No Yes 1 2 in the right shoulder 3 in the left shoulder 4 in both shoulders	5 Shoulders No Yes 1 2 in the right shoulder 3 in the left shoulder 4 in both shoulders	6 Shoulders (both/either) No Yes 1 2 2
7 Elbows No Yes 1 2 in the right elbow 3 in the left elbow 4 in both elbows	8 Elbows No Yes 1 2 in the right elbow 3 in the left elbow 4 in both elbows	9 Elbows (both/either) No Yes 1 2
10 Wrists/hands No Yes 1 2 in the right wrist/hand 3 in the left wrist/hand 4 in both wrists/hands	11 Wrists/hands No Yes 1 2 in the right wrist/hand 3 in the left wrist/hand 4 in both wrists/hands	12 Wrists/hands (both/either) No Yes 1 2
13 Upper back No Yes	14 Upper back No Yes 1 2	15 Upper back No Yes 1 2
16 Lower back (small of the back)	17 Lower back No Yes 1 2	18 Lower back No Yes 1 2
19 One or both hips/thighs/buttock	20 Hips/thighs/buttocks	21 Hips/thighs/buttocks
22 One or both knees	23 Knees No Yes 1 2	24 Knees No Yes 1 2
25 One or both ankles/feet	26 Ankles/feet No Yes	27 Ankles/feet No 1 2 2

Figure 2 Musculoskeletal questionnaire

NORDIC MUSCULOSKELETAL QUESTIONNAIRE (Bangla)

নরভিক মাসক্লোছেলিটাল প্রশ্নাকণী দয়া করে উত্তরের জন্ম সঠিক বঙ্গে (আপনার জন্য যেটি প্রযোজ্য) টিক দিন প্রতিটি প্রশ্নের জন্য একটি টিক চিফ ব্যবহার করুন

বিঃ দ্র ঃ দরা করে সকল প্রশ্নের উত্তর দিন, যদিও আপনার শরীরের কোন অংশে সমস্যা না থাকে। উল্লেখিত সমস্যা সমূহের জন্য (অবিরাম অপত্তিকর বিগত ১২ মাসের মধ্যে, যে কোন সমরে আপনি কি বিগত ৭ দিনের মধ্যে আপনি কি কোন ধরণের विषया, बाधा, अववि, अवन) विषठ ১২ मारमत নিমে উল্লেখিত শরীরের অংশসমূহে কোন ধরনের সমস্যা বোধ করেছেন ? মধ্যে আপনি কি আপনার খাভাবিক কার্যাবলি (যেমনঃ চাকুরি, পৃহস্থলির কাজ, শথ) থেকে বিরত সমস্যা বোধ করেছেন? (যেমন ঃ অবিরাম অস্বস্তিকর বেদনা, ব্যাথা, অপ্তত্তি, অবশ) থেকেছেনঃ কাধসমূহ (এক কাধ/ উভয় কাধ) कांधनमृद 8 ভান কাঁথে ১ मा ভান কাঁধে বাম কাঁথে বাম কাঁধে উভয় কাঁধে উভয় কাঁধে কনুইসমূহ (এক কনুই / উভয় কনুই) কনুইসমূহ কনুইসমূহ ভান কনুইয়ে वाम कन्दरम বাম কনুইয়ে डेट्य कन्दरा डिड्य कम्हेर्य ১২ কজিসমূহ / হাতসমূহ (এক হাত অথবা এক কজি / উভয় হাত অথবা উভয় কজি) 8 কজিসমূহ / হাত সমূহ কজিসমূহ / হাত সমূহ ১ ু ২ ু ডান (কজি / হাত) ডান (কজি / হাত) বাম (কজি / হাত) বাম (কজি / হাত) উভয় কজি / উভয় হাত উভয় কৰি / উভয় যাত কোমর কোমর (পিঠের নিচের অংশ) 3 2 वंश 2 উক্তমন্থিদয়ের সংযোগস্থা/ উরুদ্বয় / নিতথ 2 উৰুঅস্থিদয়ের সংযোগছণ/ উৰুত্বয় / নিতম ১৯ এক অথবা উভয় (উক্তঅছিদয়ের সংযোগছল/ ১ ্ ২ ্ উক্তম্বয়/ নিতম) উভয় হাঁট উভয় হাঁটু 20 এক অথবা উভয় ঘাঁটু ২৭ গোড়ালির গাঁট/ পায়ের পাতা গোড়ালির গাঁট/ পায়ের পাতা এক অথবা উভয় (গোড়ালির গাঁট/ 20

Caregiver Strain Index [CSI] (English):

I am going to read a list of things that other people have found to be difficult. Would you tell me whether any of these apply to you? (GIVE EXAMPLES)

tell me whether any of these apply to you? (GIVE E	Yes = 1	$N_0 = 0$
Sleep is disturbed (e.g., because is in and out		
of bed or wanders		
around at night)		
It is inconvenient (e.g., because helping takes so		
much time or it's a		
long drive over to help) It is a physical strain (e.g., because of lifting in		
It is a physical strain (e.g., because of many		
and out of a chair;		
effort or concentration is required)		
It is confining (e.g., helping restricts free time or		
cannot go visiting)		
There have been family adjustments (e.g., because		
helping has		
disrupted routine; there has been no privacy)		
There have been changes in personal plans (e.g.,		
had to turn down a		
job; could not go on vacation)	1	
There have been emotional adjustments (e.g.,		
because of severe		
arguments)		
Some behavior is upsetting (e.g., because of		
incontinence; has		
trouble remembering things; or accuses people	8	
of taking things)		
It is upsetting to find has changed so much		
from his/her former		
self (e.g., he/she is a different person than he/she		
used to be)		
There have been work adjustments (e.g., because		
of having to take		
time off)		
It is a financial strain		
Feeling completely overwhelmed (e.g., because o	f	
worry about ;		
concerns about how you will manage)		
Total Score (Count yes responses. Any positive		
answer may indicate a need for intervention in that area. A		
indicate a need for intervention in that areas		
score of 7 or higher indicates a high level of stress.)		
indicates a high level of suess.)		

Caregiver Strain Index [CSI] (Bangla):

আমি কিছু সমস্যার কথা বলবো যেগুলো অনেকেই সম্মুখীন হয়েছেন।আপনি আমাকে বলবেন এগুলোর কোনটি আপনার সাথে মিলে গেছে (উদাহরণ দিন)

	হ্যাঁ=১	না = ০
নিদ্রা বিঘ্নিত হয়(যেমনঃকারণ রাতে বিছানার বাইরে ঘুরে		
বেড়াতে হয়)	i i	
অস্বস্তিকর(যেমনঃ সাহায্য করতে অনেক সময় ব্যয় হয় অথবা		
অনেক দূর থেকে আসতে হয়)		
এটি শরীরের জন্য একটি ধকল (কারণ চেয়ার থেকে উঠাতে বা		
নামাতে শারীরিক এবং মানসিক পরিশ্রম করতে হয়)		
সীমাবদ্ধতা (যেমনঃ অবসর সময়ে দেখা করতে যাওয়া যায় না)		
পরিবারের সাথে সমন্বয় সাধন করতে হয় (কারণ সাহায্য করতে		
যেয়ে রুটিন ব্যাহত হয়েছে এবং সেখানে কোনো গোপনীয়তা		
থাকে না)		
ব্যক্তিগত পরিকল্পনা পরিবর্তন হয়েছে (যেমনঃ চাকুরী ছেড়ে দিতে		
হয়েছে অথবা ছুটিতে যেতে পারেনি)		
আবেগ সংক্রান্ত সমন্বয় সাধন করতে হয়(প্রচুর তর্ক বিতর্কের		
কারণে)		
কিছু আচরণ বিরক্তিকর হয় (বিভিন্ন রকম অসংযতির কারণে ;		
মনে রাখা নিয়ে সমস্যা; অথবা চুরির জন্য অভিযুক্ত করা)		
এটা মেনে নেয়া কষ্টকর সে আগের চেয়ে পরিবর্তন		
হয়েছে(যেমনঃ সে আগের চেয়ে আলাদা ব্যক্তি)		
কাজের সাথে সমন্বয় সাধন করতে হয় (যেমনঃ বারবার ছুটি নিতে		
হয়)		
এটি আর্থিকভাবে চাপযুক্ত		
সম্পূর্ণরূপে অভিভূত হওয়া (উদ্বিগ্নতার কারণে কীভাবে		
সবকিছু নিয়ন্ত্রন করবেন সে বিষয়ে চিন্তা)		
সর্বমোট নম্বর (হ্যাঁ সূচক প্রতিক্রিয়াগুলো গণনা করুনা		
যেকোনো ইতিবাচক উত্তর সেই এলাকায় চিকিৎসার		
প্রয়োজনীয়তা নির্দেশ করবে৷ ৭ বা তার উপরে প্রাপ্ত নম্বর		
উচ্চতর স্তরের ধকলকে নির্দেশ করো)		