ECONOMICAL BURDEN AND PARENTAL STRESS ON FAMILIES OF CHILDREN WITH CEREBRAL PALSY

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

ECONOMICAL BURDEN AND PARENTAL STRESS ON FAMILIES OF CHILDREN WITH CEREBRAL PALSY

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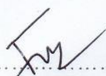
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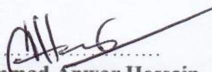
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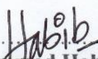
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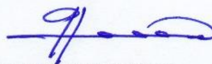
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Declaration

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

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Acronyms

BHPI : Bangladesh Health Professions Institute

BMRC : Bangladesh Medical Research Council

CP : Cerebral Palsy

CRP : Center for the Rehabilitation of the Paralysed

IRB : Institutional Review Board

SPSS : Statistical Package for the Social Sciences

WHO : World Health Organization

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Abstract

Purpose: To find out the economical burden and parental stress on families having cerebral palsy children. *Objectives:* The aim of this study was to explore the economical burden and parental stress on families which are more vulnerable for this study. To compare the burden and stress with healthy children family to CP children family. *Methodology:* A quantitative (cross-sectional) research model was carried out in the study. Purposively 50 participants of CP children mother are collected from CRP paediatric unit and 50 participants of healthy children mother at Savar, Dhaka, Bangladesh. The instruments used included direct interview a parental stress scale and a questionnaire. Data was collected by a mixed type questionnaire. Data were numerically designed. Purposive sampling technique was used for sample selection who was admitted in Pediatric unite in Centre for the Rehabilitation of the Paralysed (CRP) in Bangladesh and from the community. Data was collected by a self-demonstrate questionnaire and standard questionnaire and it was analyzed by SPSS software version 20. *Results:* The mean age of CP children was 6 years and 50 healthy children was 4 years. Mother mean age of 50 CP children was 26 years and 50 healthy children was 28 years. There was correlation between mothers stress of CP children and monthly income of the family. Mothers having CP child show more stress than the mothers having healthy child. *Conclusion:* The result of the study showed that cost of mother of CP children was more than than the healthy children mother and stress was more. More studies are needed at this area.

Key words: Economical burden, Parental Stress

CHAPTER- I INTRODUCTION

1.1 Background

Cerebral palsy is a non progressive group of permanent movement disorder that occurs in developing fetal or infant brain (Rethlefsen et al.,2010). The birth of a child with disabilities is an event that affects all family members and in the relationships between them (Nur Saadah et al., 2014). Childhood disability often imposes a social and emotional burden for children and their families (Websteret et al., 2008).

According to the World Health Survey round 785 million (15.6%) persons 15 years and older stay with a disability, while the Global Burden of Disease estimates a determine of around 975 million (19.4%) persons. Of these, the World Health Survey estimates that 110 million people (2.2%) have very considerable difficulties in functioning, whilst the Global Burden of Disease estimates that 190 million (3.8%) have "severe disability" – two the two equivalent two of incapacity two inferred two for two prerequisites such two as quadriplegia, extreme depression, or blindness. Only the Global Burden of Disease measures childhood disabilities (0–14 years), which is estimated to be ninety five million (5.1%) children, of whom 13 million (0.7%) have "severe disability"(WHO, 2011).

In United States Statistics it is estimated that there are 764,000 children and adults living with cerebral palsy. There are 2.3 to 3.6 (studies vary) of every 1,000 individuals have cerebral palsy and this prevalence can be compared with prevalence statistics in other countries. In Bangladesh childhood disability is not uncommon and cerebral palsy is a common condition (United Cerebral Palsy, 2013).

Many issues arise in a family when a child is born with CP along with caring troubles of child, cost and time related with cure and equipment, issues in social interaction of the families of a infant with disability. It is a common belief that the mother is accountable for the infant having a incapacity and household contributors are not involved to take care of the child. The mother is then left to take all responsibility of her child. So mom faces many types of issues like bodily problems, emotional problems, social problems etc. All these troubles have a wonderful have an impact on on mother's life. Different research

exhibit that for having a baby with CP there was once a first-rate affect on mother's relationship with other man or woman and mother's social existence two.(Heaton et al., 2005).

Caregiver burden is an important situation among the caregivers, its multidimensional response for physical, psychological, emotional, social and monetary stressors (Wijesinghe et al.,2015).

Caregiver duties are challenging for a child with special needs. It may additionally require repeated lifting and transferring of the child to help with bathing and toileting, changing diapers and clothes, and cleaning their mattress two. (Nor Saadahet al., 2014).

Another problem is cost in a family having a baby with CP. A recent study allocated the lifestyles time value of CP child. They divided the cost into three categories, health care costs, productivity costs, and social costs. Life time cost for children with CP is higher than the Women with CP. Cost are increasing with the age of child older. (Kruse et al., 2009).

Many mothers have a poor relationship with other family member and are often confined to the home and restricted in social and community activities. The impact of these, result in emotional stress among the mothers which is likely to affect mother's caregiving capacity (Webster et al., 2008). So Mothers try to cope with these problems. Mothers use different coping strategies for example some mothers try to solve the problems and some blame their fate and avoid negative feelings.

Health seeking behavior is the most importance means for a household having CP child. Out- of-pocket expenditure for health care is the most important means of health care troubles in developing world and form a massive share of a household financial plan. A large and unpredictable fitness value can put off a family at most excessive and poverty. The out-of- pocket repayments is including medical fees, person fees for public care, purchases for medicine, repayments for appliances, diagnostic assessments and so on (Van Doorslaer et al., 2006).

For this excessive health fees can expose a household to a considerable financial chance in view that such prices raising the stage and extent morbidity (Nazmul et al 2015)

Over the previous decades.1-3 Global information show a massive majority of children with disabilities live in low- and middle-income countries. This improved number of children with disabilities is associated with a larger number of caregivers (Wijesinghe et al., 2015). For having a child with incapacity many difficult situation may additionally be created in a household and most households are unprepared to cope with its incidence (Nur Saadaah et al., 2014). The realistic day to day wants of the child creates challenges for the mother of the child. A range of research have examined the every day challenges and troubles faced by mothers who have a child with CP (Raina et al., 2005).

In these studies it was once found that mothers face physical, emotional, social, and cost-efficient troubles as nicely as many kinds of troubles for their baby like they face troubles for taking care of their child, doing all family works with child, looking for care for child remedy and going outside of domestic with child. All these problems have a great affect on mother's life. A cerebral palsy infant has many issues in early life. Mother have to give unique care for this child. A cerebral palsy infant has faces many issues like pain, sleep disturbances, elevated strength requirements, stress sores and many others these all are involves with excessive price (Hoving et al., 2008).

Different studies show that mothers cope with their problems in these areas following some coping strategies Coping strategies used by mothers were different due to the following factors poverty, mother's educational background, external and internal resources (Taanila et al., 2008). But using a right coping strategy is very important for mother. If mother can't cope with their problem then it will cause more stress and it will affect the mother's health as well as her child's health. So it is very important to use appropriate coping strategies in an appropriate situation to help the mother with her problems (NurSaadaahet al., 2014)

In Bangladesh there are also many studies about mothers of child with CP such as problems and difficulties faced by mothers of children with CP, their stress level, their reasons for stress, economical burden.(Mobarak et al., 2000) .

Child and mortality fees being lots higher in poorest households than in the non poor in Bangladesh. According to Demographic and Health Survey (DSH) the mortality price for teens beneath 5 years of was twice as excessive in the poorest than in the richest. There is

a giant inequality between poorest and richest. In the poorest household only one-third is probably to be taken medical care for respiratory tract infections. Similarly the use of antenatal care by using mothers are considered three fold inequalities. Many proof show that poorer going through significant economic barriers in accessing care
(Chandrasiri et al., 2012).

1.2 Rationale

Cerebral palsy is a common condition, mostly seen in developing country. Day by day there is increasing the number of cerebral palsy patient, in different areas. As Bangladesh is a developing country and the people are very poor hear. In our country the number of cerebral palsy child huge. Mother has to carry the child. Here Women carry the duty of becoming mother to a child in a society. However, the birth of a child with special needs break her feeling of capacity causing a slow and deep wound that is very difficult to heal. This makes the family face an extremely bad situation. Mothers face many problems in their life for their child with CP which may cause stress.

So it is important to know what problems mother of a child with CP face in everyday life. A child with CP is a family burden. As it is a life-long disease, its slow down the family savings. The child with always need therapeutic treatment, it creates a burden for low income family. A CP child face many problem from vary early life as speech problem, feeding problem, sleep disturbance, sores etc all are related with high cost.

Child with disability needs greater care than the normal child. Mean cost for a child with chronic disability is almost double. So a family having CP child is a greater economical burden. Child with chronic disability has many problems like acute respiratory tract infection, pneumonia, breathlessness etc than the normal child. Parents have to invest a big amount for this child from very early. Including medical cost, transport cost, using drugs, diagnosis and imaging a family give a greater share from storage. It’s a big challenge for the poorest. So as Bangladesh is developing poor country here health cost a burden for most of the family.

As a many of child with CP can’t share his/her feelings so it creates a caregiver burden for mother. The child need more care than a normal child. Every mother expect that in a time her child will understand her commend but the child with CP never or ever do this. That creates stress for a mother. Every mother expects that her child will be the support for her up-coming life. She also expect that one day her will earn and take care of the family. But it ruins when she understand that her child will never be as her expectation. This thought giving stress on mothers and over all families.

As a physiotherapy student cerebral palsy is a very common condition for us. So it is important to know the problems of a mother having a CP child. This study is about caregiver and economical burden and stress of a mother having a CP child.

1.3 Aim of the study

The aim of the study was to find out the economical burden and parental stress on families having children with cerebral palsy.

1.4 Objectives

1.4.1 General objectives

- To find out Economical Burden and Parental Stress on Families of Children with Cerebral Palsy

1.4.2 Specific objectives

- To find out Socio-demographic profile of CP children and healthy children
- To find the socio-demographic profile of mothers of CP and normal children.
- To find out the health seeking behavior of children with CP.
- To find out the economical profile on families having children with CP and healthy children.
- To find out the parental stress on families having CP children and healthy children.

1.5 Operational definition

Cerebral palsy

Cerebral palsy is a condition caused by damage to the brain, usually occurring before, during or after birth. It results in sensory motor disorders that affects the control of posture and movement and caused by birth injury, congenital defects, and infectious disease.

Economic burden:

While measurements of morbidity and mortality are key considerations for estimating the burden of disease in populations, they provide an incomplete picture of the adverse impact of ill health on human welfare. In particular, the economic consequences of poor health can be substantial.

Parental stress:

Parenting stress defines as a set of processes that lead to aversive psychological and physiological reactions arising from attempts to adapt to the demands of parenthood.

CHAPTER-II LITERATURE REVIEW

The International Classification of Functioning, Disability and Health (ICF) defines that disability is an umbrella term for impairments, activity limitations and participation restrictions and a interaction between individuals with a health condition as cerebral palsy, down syndrome and depression. It also correlate with personal and environmental factors such as negative attitudes, inaccessible transportation and public buildings, and limited social supports) (WHO,2016).

Cerebral palsy (CP) is no longer only a disorder however also a non-progressive group of permanent disease of the development of movement and posture that occur in the early childhood. It causes usually activity limitation of a child and disturbances of sensation, perception, cognition, communication. (Novak, 2014)..

The rate of cerebral palsy is high globally. Historically found that in Australia and Europe the prevalence of cerebral palsy rate ranging from 1.5 to 2.5 per 1000 live births (CDC, 2017). A study allocated that the prevalence of ID was 10.6 per 1,000 in 1991 and at 13.6 per 1,000 in 2010 (Van Naarden Braun et al., 2015).

Another recent study show significant reduction of the prevalence of CP in Europe for the birth years 1980 to 2003 (Sellier et al., 2016).

Total 80 percent of disabled people live in poor income countries (Gladstone, 2010). As Bangladesh is a developing country so the number of disabled people is high in our country. A epidemiological study show that children with disabilities aged 2 to 9 years in Bangladesh indicated a prevalence rate of 6.8%for all grades and types of disabilities.
A recent Bangladeshi study show that the prevalence of CP in Bangladesh is 3.7/1000 which is 1.5 more than Australia and Europe. There are about 700 children in shahjadpur. It is the sub district of shirajganj. There are 296 villages in Shahjadpur, total population of 561,076 an estimated 70,998 households and 12,117 live births per annum. In between them 859 children with severe physical impairment . Over half of those children (57 %) had never received any rehabilitative support or services. Only 21.1 % (182) of those

children were attending regular school and just 0.2 % were attending special schools (Khandaker et al., 2015).

A family has to faces many problems when the family has a special child. For these parents and all family members in a family faces many challenges (Masood et al.,2015).

As cerebral palsy is a non-progressive permanent developmental disorder of movement and posture with activity limitation. So there caregiver burden is higher. Different studies shows different result on it. A study examined the level of caregiver burden of a child with cerebral palsy. They show that the most important predictors were degrees of disability of the child. When a child has functional impairment and needs long term support or is dependent on parents then the parents face more challenges when providing care for their child. A study allocated that the caregivers have poorer health condition than those who have a normal child (Breast et al.,2009).

Mothers have the greater responsibility for daily care of their children so face more challenges and face with more child care related stress than fathers. Having a child with cerebral palsy mother experiences physical, emotional and social suffering (Penchant et al.,2003).

The burden of everyday care giving and the increased care demands of the child creates physical pressure on mother (Hartley et al 2005). Family members of some mothers are unwilling to be involved in providing care for the child with a disability. Some fathers also believed that caring is not their primary role and their wife is solely responsible for caring for their child and all care giving responsibilities alone. The increased physical care needs of her child as well as having to complete all domestic responsibilities result in physical strain of mothers (Pelchat et al.,2003).

Mothers face problems emotionally when they don't get proper health and education service for their child. A lack of information and services are contributing factor to the emotional stress experienced by mothers. (Brehaut et al.,2009).).

Mother felt frustrated and powerless when they tried to integrate therapy into their daily life at home but didn't see any progress in their child due to not being able to implement therapy on their child properly. Their children would cry and display a lack of motivation to actively engage in treatment programs so stress was increase among the mother (Calderon et al.,2011).

Children with disability like cerebral palsy, need extra care and extra services like food, clothing, hospital charges, transport, schooling, and assistive devices such as wheelchairs etc. Lack of fund for these services or poverty is a contributing factor for mothers stress (Hartley et al 2005).

Higher level of disability always correlates with higher level of care giver burden. In many cases when a child has cerebral palsy the family members or relatives of mother and community people view mothers negatively. They were blamed for their child disability and many people regarded it as a punishment of mothers. Mother also faces problems when admitting her child at school. Mothers felt powerless and frustrated when their child was the victim of personal prejudice, and when their child faces difficulty with their peer group. For many times they are less interested to leave their child with someone else or relatives those whose family has more functional disability child. (Wijesinghe et al., 2015).

All these problems and experiences impact on the mother's life. When caring for a child with cerebral palsy, mothers do not get enough time to fulfill other roles in the family. It also creates extra pressure on the mothers' physical health and creates poor relationships with family members. Caring for their child also restricts spontaneity of mother which limits everyday activities of mother and in many ways disconnects mothers from their community (Huang et al.,2010).

Coping with the problems that arise from having a child with disabilities is a highly individual process and there is evidence to suggest that some families and mothers may never adjust fully to this event (Gibson, 1995). Parenting stress is more when the child born with disability than a child born without disability. In that case anxiety and depression of parents increase more. For that parents deals with some way that is adversely affect their parenting ability and it leads to difficulties for the children then lead more parenting stress (Parkes et al., 2011).

Another study allocated that parents children with cerebral palsy have lower level quality of life and they show more depression than general population. In this study all most 40% of caregivers showed mild to severe symptom. They concluded that parents anxiety is related to life events when they received diagnosis and they stated that anxiety can lead to

depression over time. The stress is more when the condition is chronic (Guillamon et al., 2013)

There is no significant relationship between parenting stress and the severity of child motor impairment as classified using Gross Motor Function Classification System (GMFCS). Parenting stress mainly depends on parents experienced of children with severe disability and dependent. But there is relation between presence of child behavioural problems rather than severity of the child’s motor impairment. Stress mainly based on common additional problem like affecting communication and learning rather than motor impairment alone (parkes et al., 2011)

Problem-focused coping strategies are used to tackle the problem directly. They involve managing the source of stress by confronting the problems, generating strategies and remobilizing resources. So they also regarded as positive coping in a general sense. Emotion-focused coping strategies are used to handle feelings of distress, rather than the actual problem. Emotion-focused coping aims to change a person’s negative emotional state. This usually involves ventilation, displacement, rejection, indifference and so on. Since it does not target the problem itself, emotion-focused coping is also known as avoidance coping and negative coping (Kishore, 2011).

The aim of familial is to maintain the balance between the demand and resources. Families can do this by reducing the number of demands such as a mother can leave her job to be able to take care of her child or by acquiring additional resources such as by gathering new information on the child’s disability (Taanila et al.,2002).

Those of coping strategies emotional focused is more common among others. Mothers are more likely to share their feelings rather than solve it. They need a friend rather than financial support (Nur Saadahet al., 2014).

Caring for a child with health problems can demand greater than average time demands, medical costs, employment constraints, and childcare challenges. These demands may affect the health of caregivers, a notion supported by a variety of small-scale

observational studies that have shown increased levels of stress, distress, emotional problems, and depression among caregivers of children with health problems (Brehaut et al ., 2009). Social factors such as land ownership and household income also had a negative relationship with maternal stress. Episodes of illness account for 21% of families in Bangladesh slipping further down the poverty scale. Having to care for a child with serious physical disability may also consistently reduce the limited resource of family. It cost money for these family to access services for their child especially travel cost and money for medicine, aids and so forth (Mobarak et al., 2000)

Interestingly, rural residence was not only a marker for low income as both these variables are independently associated with caregiver burden. While poverty increases the burden for both those who live in urban and rural areas, those who live in rural areas likely have less access to both formal and informal support. The lack of rehabilitation facilities in rural areas and a public transport system that does not cater to the needs of the disabled poses an additional burden for these caregivers as they have to travel frequently to the cities even for routine therapy

Sessions (Wijesinghe et al., 2015)

As CP is a lifelong condition; disability increases with age, and ageing occurs earlier. An Australian study allocated that the likelihood and severity of associated impairments increases with the severity of motor impairment. It reported that for individuals with a severe motor impairment up to 70% will have epilepsy, 50% will have a severe intellectual impairment, 55% will be nonverbal, 25% will be blind and 3% will be deaf. Many will have a number of these impairments, and their presence complicates therapy, decreases health status and quality of life for the individual and their family, and increases costs for the family and society (Australia 2008).

Treatment is not limited to the services of medical professionals, with the majority of work to manage CP being done outside of formal care settings. The role of the treatment team is often to act as a coach or mentor giving people with CP and their carer’s methods and strategies to practice at home. While mastering specific skills is an important focus of treatment on a day-to-day basis, the ultimate goal is to help people with CP grow into adulthood with as much independence as possible. As a child with CP grows older, the

need for therapy and the kinds of therapies required, as well as support services, will likely change. Counseling for emotional and psychological challenges may be needed at any age, but is often most critical during adolescence. Depending on their physical and intellectual abilities, adults may need help finding attendants to care for them, a place to live, a job, and a way to get to their place of employment (Australia 2008).

The out-of-pocket cost healthcare expenditures on family in Bangladesh is 64.3% of total health expenditure and in yearly spent approximately Taka 103.46 billion. Purchasing pharmaceuticals is the most special feature in Bangladesh for high out pocket cost. Purchasing drugs and medical cost nearly 62% of the health care expenditure. The high proportion of expenditure on drug reflects a high level of self-treatment and self-medication and medical expenditure for diagnostic and imaging is about 10%. A family spend a important portion of family income on transportation is about 6.2% related to health care service and facilities (i.e ambulance/car rental). A family spent 7.5% of its family income and 20% poorest spent approximately 13.5% of their in come for health care. As Bangladesh is a developing country, hence the health care services have been very costly in Bangladesh (Nazmul and Abuquasem 2015).

Stress among family caregivers can be defined as a problem of finance, emotions, conflict, fatigue of being a caregiver, health status, and family life change

The disease associated with high care giver anxiety levels such as chronic diseases like cancer lifelong disability, in which diagnosis correlates closely with prognosis. A study found that there is no significant relationship between maternal age and caregiver burden and stress. They are literally confirm and expect that the greater the family resources the lower caregiver burden (Calderon et al., 2011)

Many of mothers voice concerns related to increased mental stress and they worry they will not be able to meet the needs of the child and overcome the burden without outside help (Nursaadah et al., 2014).

A recent study found that high proportion of mother having child with in Bangladesh suffer from stress behavioral problem. These children were found to be strongest predictor of maternal stress. (Mobarak et al., 2000).

A Malaysian study allocated that Behavioral problem with the children are the most significantly associate with the children. The most prevalent the most behavior problems were those that consumed a considerable amount of the mothers time that is the burden of care related to lack of independence , sleep problems, bed wetting, soiling, hyperactivity and also found that the level of stress in Malaysian mothers of children with CP was modified by factors such as increased care-giving burden. Usually mothers are expected to care about two or three years, if that duration exceeds they seem to feel more maternal stress (Nur saadah et al., 2014).

Other studies which show that mothers in similar situations show higher levels of stress and depression than fathers (Pelchat et al., 2003).

When these mothers are stressed, they are reported to experience neck pain and muscle spasms related to the extreme pressures required of them as a caregiver. Stress can also lead to cognitive function problems and loss of focus with difficulty remembering. Parenting stress directly affected maternal depression and parent–child interaction. Parenting stress has been associated with both the maltreatment of children with disabilities and increased potential to abuse children with disabilities. In these study experiences of five mothers obtained by the authors found that the mothers were suffering mainly four types of stresses such as financial, emotional, environmental, and health. Stress is always referred to as a feeling of worry, burden, and anxiety (Nur Saadah et al., 2014).

CHAPTER-III METHODOLOGY

The major aim of the study was to find out the economical burden, parental stress and caregiver burden on families having CP child.

3.1 Study design

The study has done by using quantitative type of study design. This methodology was chosen to fulfill the aim of the study as an effective way to data collection.

3.2 Study site:

Paediatric unit of the Centre for the Rehabilitation of the Paralysed (CRP),Savar and a school and community was selected as the study site. The investigator thought that those area will be easy to collect data from normal children mother.

3.3 Study area

Data was collected from the Paediatric unit of the Centre For the Rehabilitation of the paralyzed (CRP), savar. At first researcher developed a questionnaire and select the mothers having CP child and having normal child. Because CRP, savar has a lot of CP children mother who were stayed and visited from different parts of whole Bangladesh.

3.4 Study population and sample population

All mothers having CP child in Bangladesh were the target population and sample population were those who came to CRP to receive treatment during the investigator study time And those mother having school going child.

3.5 Sampling procedure

Purposive sampling technique was used for sample selection. Purposive sampling starts with a purpose in mind and the sample is thus selected to include people of interest and exclude those who do not suit the purpose. Usually, the population is too large for the

attempt to survey all of its members. A small, but carefully chosen sample can be used to represent the population. The sample reflects the characteristics of the population from which it is drawn.

3.6 Inclusion criteria

- Mothers having children with CP.
- Mothers having normal child.
- Mothers who's child's Age rang is between 3-10
- Mothers who are willing to share information with researcher

3.7 Exclusion criteria

- Mothers who are not willing to share information with researcher
- 2. Mothers who have any psychological disorder.
- 3. In which mother is not primary caregiver.
- 4. Patient have any pathological condition were excluded.

3.8 Data collection

3.8.1 Method of data collection

Data was collected by using valid parental scale and a structured questionnaire paper set, developed by the investigators with the guideline of the supervisor and conducting an observation to collect information. Before the data collection, researcher proposal was submitted to the ethical review committee of BHPI for approval and to CRP ethical committee for getting permission for data collection. After the proposal was approved to carry on with the study the researcher had move to study. Then the researcher has to collect the approval to carry out with study from In-charge of the pediatric unit of CRP. Before the data collection patient were informed about the aim and objective of the study. The researcher has ensured the confidentiality of all the participants. It was been

explained to all the participants that their personal identity will be kept confidential. During the data collection, questionnaire was given to the participant and after completion, the researcher received a written consent from every participants including signature. Then this information was anonymously code to ensure confidentiality and not personally identified in any publication containing the result.

3.8.2 Data collection tools and materials

The questionnaire sought information on identification demographic information, Economical information. The researcher was also used pen and pencils, laptop approved questionnaire and, SPSS (Statistical Package for the Social Science) 20.0 versions software, collecting and interpreting data in this study.

3.8.3 Data analysis

Descriptive and inferential statistics were used for data analysis. Data was calculated in frequency and presented by using table by SPSS software version 20. In inferential statistics Chi Square test was used to show association between variables

SPSS is a comprehensive and flexible statistical analysis and data management solution. SPSS can take data from almost any type of file and use them to generate tabulated reports, charts, and plots of distributions and trends, descriptive statistics, and conduct complex statistical analyses.

3.8.4 Chi Square test

Chi square x^2 test is a nonparametric test of statistical significance for bivariate tabular analysis with a contingency table. Chi square helps us analyze data that come in the form of counts.This test can be applied to nominal or categorical data. The most common application for chi square is to determine whether or not a significant difference exists between the observed counts of cases falling into each category and the expected counts based on the null hypothesis. It is often used to compare two proportions.

3.8.5 Situations for Chi Square test

- Test of association between two events in binomial samples.
- Test of association between two events in multinomial samples

3.8.6 Assumptions for Chi Square test

- The data must be in the form of frequencies counted in each of a set of categories.
- The total numbers observed must exceed 20.
- The expected frequency in any one fraction must not normally be less than 5.
- All the observations must be independent of each other. In other words, one observation must not have an influence upon another observations.

3.8.6 Calculation of (x^2) Statistic

Chi square is the sum of the squared differences between observed (O) and the expected (E) data divided by the expected (E) data in all possible categories.

In contingency table problems, writer creates an index that computes for each outcome cell,

$$\frac{(\text{Observed count} - \text{Expected count})^2}{\text{Expected count}}$$

If O stands for observed count and E for expected count, the mathematical notation the formula looks like this:

$$x^2 = \sum_{\mathrm{i}=1}^{\mathrm{k}} \frac{(\mathrm{O} - \mathrm{E})^2}{\mathrm{E}}$$

3.9 Ethical consideration

Then the research proposal was submitted Institutional Review Board (IRB) for being approval. The guide of World Health organization (WHO) and Bangladesh Medical and Research council (BMRC) are also followed by the researcher This study got permission on the ethical review board. Beginning the data collection, permission was obtained from the concerned authorities ensuring the safety of the participants. The formal permission was taken from the head of the physiotherapy Dept. to check patient file and collect the data. Data collection was started and completed within the allocate time frame. All information was kept in secure. The participants were informed that the data was collected by written questionnaire. The supervisor also checked the consent form and questionnaire. For this study took permission during interview from every single participant with signature on a written consent form of the participants who were interested. The participants were informed about their role in the research process. Informed the participant about the aim of the research and procedures involved in the study. They had also informed that if they wish they were free to withdraw from the study at any time. Also mentioned the participants that the information provided by the individuals might be published but their name and address would not be used in research project. The study information only discusses with supervisor but this would not share with any other person. These materials will be disposed of after completion of the research project. The study results might not have any direct effects on them but the Physiotherapy professional may be benefited from the study in future. Participants were also informed that they would not get any harmful things from the study.

CHAPTER-IV RESULTS

The aim of the study is find out the economical, caregiver burden and parental stress on families having child with cerebral palsy. Results and discussion was carried out at same time and presented together.

4.1: Socio-demographic information (Age group and Education level)

In this study total participant was 100, 50 participant was CP children and 50 participant was healthy children. Mean age of Cp children was 4 years and healthy children was 6 years. Gender of CP children male was 31(62%)person, female was 19(38%) and for healthy children male was 23(46%)person, female was 27(54%). There was 4% hemiplegic,15% diaplegic, monoplegic 2%, quadriplegic 76%. Mean age mother of CP children was 26 years and 28 years was healthy children mother. Father mean age of CP children was 35 years and healthy children was 36 years. The study was show that mother and father education of CP children and healthy children. Among 50 participants of CP mother was 26% was primary educated 46%, high school level was 46%, higher secondary was 18% and among 50 healthy children mothers 18% was primary level, 30% was high-school level 28% was higher secondary level . Among 50 CP children father 16% was primary level, 32% was high-school level, 12% was higher secondary level and among 50 healthy children fathers 16% was primary level, 32% was high-school level, higher secondary level was 20%.

Table no 4.1: Socio-demographic information (Age group and Education level)

Age	Frequency	Mean age(years)	Std.deviation
CP children	50	4	1.77
Healthy child	50	6	1.6
Gender (CP children)		percentage	
Male	31	62%	
Female	19	38%	
Gender (Healthy children)			
Male	23	46%	
Female	27	54%	
Type of CP			
Hemiplegic	2	4%	
Diaplegic	9	18%	
Monoplegic	1	2%	
Quadriplegic	38	76%	

Table no 4.1: Socio-demographic information (Age group and education level)

Age of mother	Frequency	Mean age (years)	Std,deviation	
CP children	50	26	5.10	
Healthy children	50	28	3.39	
Age of father				
CP children	50	35.32	7.17	
Healthy children	50	36.48	4.96	
Mother Education	**CP Children**		**Healthy Children**	
	Frequency	Percentage	Frequency	Percentage
No formal education	1	2%	8	16%
Primary level	13	26%	9	18%
High-school level	23	46%	15	30%
High-secondary	9	18%	14	28%
Graduation	4	8%	4	8%
Father Education				
No formal education	6	12%	2	4%
Primary level	8	16%	8	16%
High-school level	16	32%	16	32%
Higher-secondary	6	12%	10	20%
Graduation	13	26%	14	28%

4.2: Socio-demographic information (Employment)

Among 50 CP Children mothers 2% was teacher, 4% was doing business, 2% was garments worker,92% was housewife and Among 50 healthy children mothers 2% was teacher, 20% was garments worker,70% was housewife, 2% was service2% was tailor. Among 50 CP children fathers service holder was 22%, farmer was 12%, teacher was 6%, garments worker was 8%, shopkeeper was 10%, Driver was 2%, lives abroad was 10%, mason was 8%, business man was 18%, police was 2%, ved was 2%. Among 50 healthy children father, service holder was 22%, teacher was 4%, garments worker was 34%, tailor was 4%, shopkeeper was 16%, rickshaw puller was 4%, lives abroad was 6%, mason was 2%, business man was 8%.

Table no 4.2: Socio-demographic information (Employment)

Mother Employment	CP Children		Healthy Children	
	Frequency	Percentage	Frequency	Percentage
Housewife	46	92%	35	70%
Garments worker	2	4%	10	20%
Business	1	2%	3	6%
Teacher	1	2%	1	2%
Tailor			1	2%
Father Employment				
Service holder	11	22%	11	22%
Teacher	3	6%	2	4%
Garments worker	4	8%	17	34%
Shopkeeper	5	10%	8	16%
Lives abroad	5	10%	3	6%
Mason	4	8%	1	2%
Business	9	18%	4	8%
Police	1	2%		
Rickshaw puller			2	4%
Tailor			2	4%
Ved	1	2%		
Farmer	6	12%		
Driver	1	2%		

4.3 Socio-demographic information (Living area and family members)

In this study Among 50 families of CP children rural was 76%, urban 6%, sub-urban 18% and among 50 families of healthy children 6% rural, urban 8%, sub-urban 86%. Mean family members of CP children families was 5 person and members of healthy children family was 4 person.

Table no 4.3: Socio-demographic information (Living area and family members)

Living area	**CP child families**		**Normal child families**	
	Frequency	percentage	Frequency	percentage
Rural	38	76%	3	6%
Urban	3	6%	4	8%
Sub-urban	9	18%	43	86%
Family members	**Mean**		**Standard deviation**	
CP child families	5		2.52	
Normal child families	4		1.49	

4.4 Health seeking behavior of CP children families

Among 50 participant 90% was start treatment immediately after diagnosis and 10% did not go anywhere after diagnosis.

Table no 4.4: Health seeking behavior of CP children families

Siblings Disability	**Frequency**	**Percentage**
Disability present among CP child siblings	5	10%
Disability absent among CP child siblings	45	90%
Condition diagnosis		
Medical diagnosis	44	12%
Non-medical diagnosis	6	88%
Treatment started		
Immediately after diagnosis	45	90%
Did not go anywhere except CRP	5	10%
Therapy was taken before came to CRP	23	46%

4.5 Caregiver information of CP children

In this study 50 CP children mothers stated that maximum 12 hours and minimum 3 hours need for the of CP child.

Table no 4.5: Caregiver information of CP children

	Maximum	Minimum	Mean
Hours needed for care of CP child	12	3	7.14
Planned for another child of CP mother		**Frequency**	**Percentage**
	Yes	18	36%
	No	32	64%
Mother perception of another child could be the same problem	Yes	8	16%
	No	28	56%
	Undecided	14	28%

4.6 Economical information of CP child family and healthy child family

Out of 50 CP child families the range of monthly income was 67000tk in between minimum income was 3000tk to maximum 70000tk. The mean income is 18180 and the standard deviation was 13466.o4.Out of 50 normal child families the range of monthly income was 60000tk in between minimum income 10000tk to maximum 70000tk. The mean income is 26020 and the standard deviation was13562.38**.**

Among 50 CP child families the range of monthly expenditure was 47000tk in between minimum expenditure 3000tk to maximum 50000tk. The mean expenditure is 17060 and the standard deviation was 11728.92813.Among 50 normal child families the range of monthly expenditure was 57000tk in between minimum expenditure 3000tk to maximum 60000tk. The mean expenditure was 23260 and the standard deviation was 13198.34560.

Table no 4.6: Economical information of CP children family and healthy children family

Monthly income	Minimum(tk)	Maximum(tk)	Mean(tk)	Std.deviation(tk)
CP child family	3000	70000	18180	13466.04
Healthy child family	10000	70000	26026	13563.38
Monthly Expenditure				
CP child family	3000	50000	17060	11728
Healthy child family	3000	60000	23260	13198
Monthly Extra Expenditure				
For CP child	500	1200	4650	3224.99
Healthy child	400	1500	3708	3123.57

Earning Member	Earning member of CP child family		Earning member of normal child family	
	Frequency	Percentage	Frequency	Percentage
Father	44	88%	32	64%
Father+ Mother	1	2%	15	30%
Father+ Uncle	4	8%	2	4%
Father+uncle+ Grandfather	1	2%		
Father+ Grandfather			1	2%

Source of money	Frequency	Percentage
Personal savings	6	12%
Family support	4	8%
From earning source	26	52%
Support from govt.	1	25%
Loans	2	4%
Family support+ Earning source + loans	10	
Family support+ earning source		20%

4.7 Parental Stress

The stress of CP children mothers was 92% and healthy children 70%.

Table no 4.7: Mother Stress of CP and Healthy children

	Mean(Percentage)	**Standard deviation**
Mother stress CP child	82.8(92%)	7.8
Mother stress of Healthy child	63.3(70%)	8.4

Table no 4.8.1: Distribution of respondents with level of education and stress of mother's of CP children

Level of stress		51-60	61-70	71-80	81-90	Total
Level of mother education	No formal education	0	0	1	0	1
	Primary level	0	0	5	8	13
	High school level	1	1	3	18	23
	Higher secondary level	1	1	2	5	9
	Graduation	0	0	0	4	4
Total		2	2	11	35	50

Among 50 Participants the level of stress range 51-60 was 2 participants, stress range 61-70, 2 participants, stress range 71-80, 11 participants, stress range 81-90, 35 participants. The stress level was 1 when the education level was high school, stress 13 when education level primary level, stress 23 when education level high-school level, stress 9 when education level higher secondary, stress 4 when education level was graduation.

Table no 4.8.2: Association between level of education and stress of mother's of CP children

Level of stress and Level of mother education	Chi squire	p value
	11.655	0.474

This observed Chi-square value was 11.655 and 5% level of significant state chi-square was 1.96 which is less than the observed chi-square value. That means Null-hypothesis was neglected and alternative hypothesis was accepted. So the result was not significant that indicate there was strong association between level of stress and level of mother education.

Table no 4.9.1: Distribution of respondents with monthly income and stress of mothers of CP children families

		Level of stress				
		51-60	61-70	71-80	81-90	Total
Monthly Income	1000-10000	0	0	4	22	26
	11000-20000	2	1	4	7	14
	21000-30000	0	0	2	2	4
	31000-40000	0	0	1	2	3
	41000-50000	0	0	0	2	2
	61000-70000	0	1	0	0	1
Total		2	2	11	35	50

Participants whose families income was 1000-10000 level of stress of participants was 26,in between monthly income 11000-20000 the level of stress of participants was between 14, in between monthly income 21000-30000 the level of stress participants was 4, in between monthly income 31000-40000 the level of stress participants was 3, in between monthly income 41000-50000 the level of stress participants was 2, in between monthly income 61000-70000 the of stress of participant was 1.

Table no 4.9.2: Association between monthly income and stress of mothers of CP children families

Level of stress and Monthly income	Chi squire	p value
	35.765	0.002

This observed Chi-square value was 35.765 and 5% level of significant state chi-square was 1.96 which is less than the observed chi-square value. That means Null-hypothesis was neglected and alternative hypothesis was accepted. So the result was significant that indicate there was strong association between level of stress and monthly income.

Table no 4.10.1: Distribution of respondents level of education and stress of mother's of healthy children

Level of stress					
		51-60	61-70	71-80	Total
Level of	No formal education	3	3	2	8
Mother	Primary level	1	3	5	9
Education	High school level	5	6	4	15
	Higher secondary level	10	1	3	14
	Graduation	2	2	0	4
Total		21	15	14	50

Among 50 Participants the level of stress range 51-60 was 21 participants, stress range 61-70, 15 participants, stress range 71-80, 14 participants. The stress level was 8 when the education level was formal education, level of stress was 9 education level was primary level, stress 15 when education high school level, stress 14 when education level higher secondary level, stress 4 when education level was graduation.

Table no 4.10.2: Association between level of education and stress of mother's of healthy children

Level of education and Stress of mother	Chi squire	p value
	12.76	0.120

This observed Chi-square value was 12.76 and 5% level of significant state chi-square was 1.96 which is less than the observed chi-square value. That means Null-hypothesis was neglected and alternative hypothesis was accepted. So the result was not significant that indicate there was strong association between level of stress and level of mother education.

Table no 4.11.1: Distribution of respondents monthly income and stress of mothers of healthy children families

Level of stress		51-60	61-70	71-80	Total
Monthly income	1000-10000	0	3	0	3
	11000-20000	9	8	8	25
	21000-30000	7	2	4	13
	31000-40000	1	0	0	1
	41000-50000	2	2	2	6
	51000-60000	1	0	0	1
	61000-70000	1	0	0	1
Total		21	15	14	50

Participants whose families income was 1000-10000 level of stress of participants was 3,in between monthly income 11000-20000 the level of stress of participants was between 25, in between monthly income 21000-30000 the level of stress participants was 13, in between monthly income 31000-40000 the level of stress participants was 1, in between monthly income 41000-50000 the level of stress participants was 6, in between monthly income 61000-70000, the of stress of participant was 1.

Table no 4.11.2: Association between monthly income and stress of mothers of healthy children families

Level of stress of mothers and monthly income	Chi squire	p value
	13.11	0.360

This observed Chi-square value was 13.11 and 5% level of significant state chi-square was 1.96 which is less than the observed chi-square value. That means Null-hypothesis was neglected and alternative hypothesis was accepted. So the result was not significant that indicate there was strong association between level of stress and monthly income.

CHAPTER-V DISCUSSION

The aim of the study was to find out the economical burden, caregiver burden and parental stress among CP child mother and healthy child mother. A self structured questionnaire to find out the economical burden and a valid parental stress scale is the instrument that evaluates the economical burden and parental stress on families having child with cerebral palsy.

As the researcher main objective was find out economical burden of Children with CP family. The result of the study mainly indicated the economical burden of family with cerebral palsy. Researcher found that the maximum monthly extra expenditure for the CP child is 12000tk on the other for healthy child need 15000 maximum per month. As the average income of Bangladesh is 14000tk, the extra-expenditure is very demanding for them. A recent Australian study analysis the emphasizes the depth of poverty of many more millions people in Asia and they showed that the prevalence and the depth of poverty increased in Asia due to cost for health care .Over 78 million people from low income to middle income countries are fell below the extreme poverty and the out pocket cost per day for health care is $1 (Van Doorslaer et al., 2006). In other study show that Families having children with special care need faces more complex exceptionally high care demands. In these family increased unemployment and a financial burden that many more complex unmet medical needs. The study also show that Children with special medical care need has high care burden. They show that most families with more complex children with special care need visits physician at least last 12 months and more than 11 missed school. The total out-of-pocket health care payments annually $1000. In these family more than 175000 parents leave their job to stay at home for care their child with high medical complexity (Kuo et al., 2011).

Researcher found that family having CP faces extra medical cost as the family with healthy faces mainly educational and recreational cost. A study show that individuals with CP faces higher cost as social cost, health care cost than the individuals without CP (Kruse et al., 2009).

In this study researcher found that among 50 CP child families only one have monthly income 70000 but all are in average. In Bangladesh socio-economic status has been previously identified as a strong predictors of health seeking behavior for under 5 years children. Even not only Bangladesh also many other low income countries. A study suggests that the rich people are more likely to seek quality of life than poor group (Najnin et al., 2011). With low income people have to face extra expenditure.

In the result section researcher noted that among fifty families monthly extra expenditure for CP child was more than our country's mean income as maximum 12000tk and minimum 500tk in between mean was 4650tk and for healthy child maximum extra expenditure 15000tk ($185), minimum 400tk in between mean 3708tk . A china's study estimated that still they found health care access is unaffordable and expensive (Zhang and Liu, 2013).

As researcher noted the result section the most predictor care giver burden is need extra hours for care. CP child mother needs care maximum 12 hours, minimum, mean, 7.14 hours of CP child. In the study mother have to care at least 7 hours of child. This creates a burden for the mother and bad impact on mothers health. An another study find the psychological distress and anxiety level among the caregivers. They show relation between psychological stress and the time need for their children. They show that maternal trait anxiety negatively affects psychological distress and in turn psychological distress negatively associate with the caregivers perception with time and afford required to care for their children. They also show that the perception of stress higher among the mothers chronically ill children and the complexity of chidren problems influence caregiver heath more than the severity of the disease (Calderon et al., 2011).

A recent study about caregiver perception CP mother, they share their experiences and beliefs that their health is affected by the tasks of care giving. Care giving task impact their physical and mental health and in combination perceive anxiety about their child's health and future. Often they neglect their own health regarding their children with disabilities and their families as a whole. Most of the mother believes that they face significant barriers improving their own health. As a lack of time, lack alternative care providers for the child and low prioritization of the need parents face barriers to

promoting their own health. (Murphy et al., 2007). Another study show that the most significant predictor of caregiver burden was the degree of disability/ dependence of children (Maroon et al., 2013).Also another study showed that Children with chronic disabilities was predictor of caregiver burden (Riana et al., 2005). Another study they compare with the caregivers of the children with health problem and healthy children. They show that the caregiver's health is significantly poorer than the caregivers of healthy children. They allocated that Caregivers of children with health problem show more chronic conditions, activity limitation, poor general health and symptoms of depression than caregivers of healthy children (Brehaut et al., 2009).

In this study researcher found that among 50 CP mother 36% were planned for another child following CP child and 64% were not planned for CP child. 16% mother thought that the next child will be the same problem, 28% mother were undecided for the next child, 56% mother belief that the next child will be normal. A study allocated that Caregiver burden is an important concern among caregivers of children with cerebral palsy. In this study they find some factors associated with caregiver burden. The Show that the demographic variables rural residence, low income, and male child all remained significantly associated with caregiver burden. While poverty increases the burden for both those who live in urban and rural areas. The lack of rehabilitation facilities in rural areas and a public transport system poses an additional burden for these caregivers as they have to travel frequently to the cities even for routine therapy sessions. They also show that that community-based rehabilitation programs can be a cost-effective of people with disabilities in rural areas (Wijesinghe et al., 2015).

The purpose of the study was also find out parental stress and the relation between mother stress with CP child. Mother stress develops when a mother understood the child behavioral problem. A study show that maladaptive behavior explained in specific parts of parental stress. A study allocated that child showed that behavior problems have both direct and indirect effects on parental stress and Child behavior problems were an important predictor of caregiverpsychological state, both directly and indirectly effect on family function. They also show that parental stress and child's behavior affect one another: as child behaviour becomes increasingly troubling, parental stress increases, and behavioural problems are, in turn, exacerbated (Ketelaar et al., 2008).

The cross tabulation of parental stress the showed that higher level of stress having CP child mother whose educational level was high school level. Another cross tabulation showed that the higher level of stress present on those family who were not economically fit and high income family had low level of stress according to Bangladeshi background. A study used parental stress scale to compare stress between the children with CP caregivers and the children with autistic caregivers. They found that caregivers having children with CP has higher stress than the caregivers with autistic children. They obtained that caregivers having children with cerebral palsy experience more caregiver burden. The study also conducted that caregiver having children with cerebral palsy use less coping strategies. Parents used reframing strategy that helps them to cope with the situation. (Pushpalatha and Shivakumara, 2016). In the study researcher could not find huge differences of stress between the mothers of CP children and the mothers of healthy children. This is similar to a other study. They analyzed a sample of 46 mothers of CP children with cerebral palsy and 46 mothers of healthy children and had not found any differences in levels of anxiety in between two groups. They summarized that parents anxiety could be related to acute life situation rather than a long lasting situation. They added that a long lasting situation is lead to depressive symptoms (Ones et al., 2005). Another study finds out the experiences of mother and father of parenting a child with disability. They supported that mothers in similar situations show higher levels of stress and depression than fathers (Pelchat et al., 2003)

In this study researcher also researcher found that the as the level of education is lower the level of stress is higher with the mother of children with CP. The cross tabulation show that the stress level is higher when the education level is high school level of mother with CP children. In this study researcher found that the mean age of 50 CP child mothers was 26 year and the mean age 50 healthy child mother was 28 year. The study showed the education level of 50 CP child mother no formal education 2%, primary level 26% high- school level 46%, Higher-secondary level 18%, post-graduation 8% .Among 50 healthy child mother no formal education is 16%,primary level 18%, high-school level 30%, higher-secondary level 28%, post-graduation 8%. Employment of CP child mother 92% were housewife, 4% were garments worker, 2% were business work, 2% were

teacher and employment of 50 healthy child mother house wife were 76%, garment worker 20%, business work 6%,teacher 2%, tailor 2%.

Researcher found that the source of money is also a great source of parental stress. In this researcher found the source of money for the CP among 50 families 12% from personal savings, 8% from family support, 52% from earning source, only 2% from governmental support, 2% from took loan, 20% got help from earning source, family support, and loan, only 2% from family support and earning source.

In this study researcher also conducted socio-demographic of children with CP and healthy children. In this study the mean age of children with CP was 4.8(±1.77) and the healthy children with mean age 6.5(±1.6).Researcher could not found any socio-demographical importance for CP. In a recent European study which is conduct with the children with cerebral palsy showed that socio-demographic factors are not affected in their as usual participation's children most probably suffered from impairment, walking problem, intellectual inability and pain. Variation of this problem differs from region, domains. In Denmark on average variation found in regions and sometimes in individual (Fauconnier et al., 2009).

A recent Bangladeshi study allocated that having a child with serious physical disability may limit the resources of the family. They have to face access service for their child , especially travel cost and money for medicine aids. Here the fact is that a significant number of most severely disabled children, especially from the poorest rural families and with severe malnutrition died during the follow up period (Mobarak et al., 2000). In the study researcher found that most of participants were likely to go to the trained provider. Among 50 CP child 10% have siblings disability. For the diagnosis of CP 44% got medical diagnosis and 6% got not medical diagnosis. After diagnosis CP immediately 90% started treatment and 10% did not go anywhere. At first 2% went to traditional healer, 4% village doctor, 10% thana health complex, 4%district health complex, 10% public hospital, 10% private hospital, 14% special child care centre, 14% public hospital+ special child care unit, 30%district complex+ public hospital, 2% go outside of the country, 4% did not go anywhere. Over all 90% got proper medical treatment, 6% non-

medical treatment, 4% did not take any treatment. Among 50 CP child 46% took therapy before come to CRP and 54% did not take therapy before.

Feeling of disempowered and overwhelmed by an unpredictable future mainly got parental stress and burden with the children CP. Mainly parents hope that their child will grow up healthy, with good morality, intelligence, physical health and beauty. Since parents have high expectations for their child, they do not expect that their child will have physical impairments or could be born with a disability. This expectation causes a great burden for parents.

Complete accuracy is not possible in any research so that some limitation may exist. Regarding this study, there were some limitations or barriers to consider the result of the study. The samples were collected only from the selected area at Centre for the Rehabilitation of the paralyzed (CRP). So the result of the study could not be generalized to the whole population in Bangladesh. The research project was done by an undergraduate student and it was first research project for her. So the limited experience with techniques and strategies in term of the practical aspects of research. As it was the first survey of the researcher so might be there were some mistakes that overlooked by the supervisor and the honorable teacher. The researcher used a self-demonstrate questionnaire, there was some questions that was not necessary. So the researcher had to cut some questions from data.There was some other limitations that the researcher collect data from CRP paediatric unit, could not collect data from the area where they lived for normal child due to time limitation.

CHAPTER-VI CONCLUSION AND RECOMMENDATIONS

6.1 Conclusion

Bangladesh is a developing country among the third world. The rate of education is very low. Besides government and non-government activities in health sector are not sufficient for the people live in here. Cerebral palsy is a common condition in Bangladesh. But most of the people in this country are not aware about the Cerebral palsy. This study was aimed to find out the demography, economical burden and parental on families having CP child. For the fulfillment of the study the researcher was designed a quantitative self demonstrated study design and used a parental stress scale to measure the stress of mothers of CP child and mothers of healthy child. For completed this study the researcher collected 50 data from the samples through a standard questionnaire from the registered unit of Pediatrics and 50 data from community of healthy child to compare with CP child. From the data base, it was found that the socio-demography could not affect the health. All most families were go for trained provider rather than untrained provider. The educational level of families was not good. Rich people are more likely to health care seeking than the low income families. As cerebral palsy management is a long time process, so having a CP child was a burden for low income families. There is no significant differences between of stress on families having CP child and families having healthy child.

6.2 Recommendation

The aim of the study was to assess economical burden and parental stress on families having CP child. The result which found from the study has fulfilled the aim of this research project.The main recommendations would be as follow:

- Should take more samples for generating the result and try to make more valid and reliable.
- Outcome or result can be measured in a valid scale in further studies.
- Sample should collect from many area in Bangladesh.
- Healthy Child sample should be collect from same area of Child.

This is an undergraduate study and doing the same study at graduate level will give more accurate output. There was some limitation of the study mentioned at relevant section. It is recommended to overcome those limitations during further study.

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APPENDIX

APPENDIX-1

Consent Form

I am FatemaTujJohora, 4th year student of Bsc in Physiotherapy in Bangladesh Health Profession Institute. I am conducting a research and the title is-**“Economical Burden and Parental Stress on Families of Children with Cerebral Palsy.”**which is included in my course. For that I'm asking you to answer some questions, which will not take time more than 10-15 minutes. It also ensures that the information you provide will be kept confidential.

Participation here depends on your own will. If you want, you can skip your name from the list of participants at any time. In addition, if you have any questions as a participant in this study or if there is any problem, you can contact with me or Firoz Ahmed mamin, Assistant Professor, Department of Physiotherapy, BHPI, CRP, savar Dhaka

Do you have any questions before starting the research?

Can I start this interview with your permission?

Yes ....

No ....

Participant's signature ………………………

Recipient signature …………………………

"Economical Burden and Parental Stress on Families of Children with Cerebral Palsy."

Personal details

ID No………………………………	Date of interview………………………
Contact Number………………	Address ……………………….. ………………………… …………………………..

অনুমোদন পত্র

আমি ফাতেমা তুজ জোহরা, 'বাংলাদেশ হেলথ প্রফেশন ইন্সিটিউট' এর চতুর্থবৎসরবি, এসসিছাত্রী।আমি একটি গবেষণা করছি যার শিরোনাম হল ''ইকোনোমিক্যাল বার্ডেন অ্যান্ড স্ট্রেস অন ফ্যামিলিস অফ চিলড্রেন উইথ সেরেব্রাল পালসি'',যেটা আমার অধ্যয়নের অন্তর্গত।এই জন্য আমি আপনার কাছে কিছু প্রশ্নের উত্তর জানতে চাচ্ছি,যেটাতে সর্বমোট ১০-১৫ মিনিট সময় লাগবে। এটাও নিশ্চিত করছি যে আপনি যেসব তথ্য প্রধান করবেন তার গোপনীয়তা বজায় থাকবে।

এখানে অংশগ্রহন আপনার নিজের উপর নির্ভর করে।আপনি চাইলে যে কোন সময় কোন ফলাফল ছাড়াই চলেজেতে পারেন।এ ছাড়াও যদি আপনার এই গবেষণায় অংশগ্রহন কারী হিসেবে কোন প্রশ্ন থাকে তাহলে আপনি আমাকে অথবাফিরজ আহমেদ মমিন,অ্যাসিস্ট্যান্ট প্রোফেসর,ফিজিওথেরাপী বিভাগ, বি এইচ পি আই, সাভার, ঢাকা,এরসাথে যোগাযোগ করতে পারেন।

গবেষণাটি শুরু করার আগে আপনার কোন প্রশ্ন আছে?

আমি কি আপনার অনুমতি পেয়ে এই সাক্ষাতকারটি আরাম্ভ করতে পারি?

হ্যাঁ..............

না ....

সাক্ষাৎকার প্রধানকারীর স্বাক্ষর..

সাক্ষীরস্বাক্ষর ....

''ইকোনোমিক্যাল বার্ডেন অ্যান্ড স্ট্রেস অন ফ্যামিলিস অফ চিলড্রেন উইথ সেরেব্রাল পালসি''

ব্যক্তিগততথ্য

আইডি নম্বর	সাক্ষাতকারের তারিখ....................
মোবাইল নম্বর............................	ঠিকানা ....

APPENDIX-2

Questionnaire Code…………

Section: 1 Socio-demoghraphic information			
Qn	Questions	Responses	Code
1	Age of child (in year)	(………)year	
2	Gender of Child	Male ……………………………. Female……………………………	01 02
3	Type of cerebral palsy	Hemiplegic……………… Diplegic…………………………… Monoplegic…………………… Quadriplegic……………	01 02 03 04
4	Age of mother	(………)year	
5	Mother education	No formal education…… Primary level…………………… High school level………………… Higher-secondary level………… Graduation/ Post graduation……	01 02 03 04 05
6	Mother employment	Teacher …………………………… Banker ……………….. Business …………………. Garments ………………… Tailor …………………………… Housewife ……………………	01 02 03 04 05 06
7	Age of father	(………)year	
8	Father education	No formal education…………. Primary level…………… High school level………… High-secondary level………… Graduation/ Post graduation……	01 02 03 04 05
9	Father employment	Service holder…………….. Farmer………………… Teacher………………… Garments worker……………… Tailor ………………………… Shopkeeper…………………… Rickshaw puller……………… Driver……………………… Others………………………	01 02 03 04 05 06 07 08 09
10	Living area	Rural………………… Urban………………………….. Sub Urban………………………..	01 02 03
11	Number of family members	…………………	
12	Siblings	Yes………………………………	01`

		No…………………………………	02
13	Number of siblings (..)	Sister……….. Brother…………………	01 02
14	What is the age of other child/children?	Sister………..year…..month Brother………year………month	
15	Disability present in siblings		
16	Living area	Urban ………………………… Rural………………………… Sub-rural…………………………	01 02 03
Section:2 Health seeking behavior			
1	Did you know about your child diagnosis?	………………………………	
2	When the condition was diagnosed?	……………(Age in year or month)	
3	Who diagnosed the condition?	Village doctor……………………… Tradition healer………………… Registered physician……………… Child specialist………………. Therapist…………………… Other ……………………………	01 02 03 04 05 06
4	When did you start treatment for your child?	Before diagnosis……………… Immediately after diagnosis…… Other………	01 02 03
5	Where initially did you go for treatment after diagnosis of CP ?	Non medical professional …… Village doctor/local pharmacy… Community clinic/Thana health complex............... District health complex…………… Medical college / tertiary level hospital…… Public hospital ………………… Private hospital…………………. Special child care centre…… Did not go anywhere…………	01 02 03 04 05 06 07 08 09
6	Did your child receive any rehabilitation (PT? OT? SLT?) service before coming at CRP?	Never………………………… Immediately after diagnosis… Others…………………	01 02 03
7	If yes, Where?	…………………………	
9	How long did you continue the treatment on that/ those facilities?	…………………………….	
Section: 3 Caregiver information			
1	Who is the primary care giver of the child?	Mother……………………… Father…………………… Grandmother…	01 02 03

2	How many hours care needed for this child?	……………………	
4	Do you consider that you are not able to put enough time to other household works for this child?	Yes……………… No……………	01 02
5	If sibling present, Do you consider that you are not able to give enough time for other child / children?	Yes……………………… No………………………………	01 02
6	If no sibling, Are you planning for another child?	Yes……………………………… No……………………	01 02
7	Do you think if you take another baby could have the same problem?	Yes…………………………… No…………………………	01 02
8	If in job, Did you need to quit your job for this child?	Yes………………… No…………………………………	01 02
9	If in job, Did you need to quit your job for this child?	Yes……………………… No………………………………	01 02
Section : 4 Financial information			
1	Total income of your family	…………………	
2	What is the monthly expenditure of your family?	....	01 02 03
3	Who is the earning member of the family	Father…………….. Mother………….. Others ……………………	01 02 03
4	Does any extra expenditure related with your CP child	………………………	
5	How much extra money is required purely for this child care	……………………………………	
6	Sources of money for CP treatment	Personal savings………… Family support……………… Support from job place…… Support from friends……… Support from government (who are not govtemployees) or other organization…... Selling property or other things…. Loans …………………………… Support from mother relatives..	01 02 03 04 05 06 07 08

Parental Stress Scale

QN	Questions	Response	Code
1	I am happy in my role as a parent	Strongly disagree	01

		Disagree.................................. Undecided.............................. Agree....................................... Strongly agree	02 03 04 05
2	There is little or nothing I wouldn't do for my child(ren) if it was necessary.	Strongly disagree....................... Disagree.................................. Undecided................................... Agree.. Strongly agree	01 02 03 04 05
3	Caring for my child(ren) sometimes takes more time and energy than I have to give.	Strongly disagree.......................... Disagree............................... Undecided.......................... Agree.. Strongly agree	01 02 03 04 05
4	I sometimes worry whether I am doing enough for my child(ren).	Strongly disagree....................... Disagree................................... Undecided...................................... Agree... Strongly agree	01 02 03 04 05
5	I feel close to my child(ren).	Strongly disagree....................... Disagree.................................... Undecided................................. Agree... Strongly agree	01 02 03 04 05
6	I enjoy spending time with my child(ren).	Strongly disagree............................ Disagree..................................... Undecided.................................. Agree.. Strongly agree	01 02 03 04 05
7	My child(ren) is an important source of affection for me.	Strongly disagree....................... Disagree...................................... Undecided................................... Agree.. Strongly agree	01 02 03 04 05
8	Having child(ren) gives me a more certain and optimistic view for the future.	Strongly disagree......................... Disagree...................................... Undecided................................... Agree.. Strongly agree	01 02 03 04 05
9	The major source of stress in my life is my child(ren).	Strongly disagree......................... Disagree...................................... Undecided..................................... Agree... Strongly agree	01 02 03 04 05
10	Having child(ren) leaves little time	Strongly disagree............................ Disagree....................................	01 02

	and flexibility in my life.	Undecided................................... Agree.. Strongly agree	03 04 05
11	Having child(ren) has been a financial burden.	Strongly disagree......................... Disagree.. Undecided................................... Agree... Strongly agree	01 02 03 04 05
12	It is difficult to balance different responsibilities because of my child(ren).	Strongly disagree............................ Disagree..................................... Undecided................................... Agree.. Strongly agree	01 02 03 04 05
13	The behaviour of my child(ren) is often embarrassing or stressful to me.	Strongly disagree........................ Disagree.................................... Undecided................................ Agree...................................... Strongly agree	01 02 03 04 05
14	If I had it to do over again, I might decide not to have child(ren).	Strongly disagree...................... Disagree.................................. Undecided................................. Agree...................................... Strongly agree	01 02 03 04 05
15	I feel overwhelmed by the responsibility of being a parent.	Strongly disagree........................ Disagree.................................... Undecided................................. Agree...................................... Strongly agree	01 02 03 04 05
16	Having child(ren) has meant having too few choices and too little control over my life.	Strongly disagree.......................... Disagree.................................... Undecided................................. Agree.. Strongly agree	01 02 03 04 05
17	I am satisfied as a parent	Strongly disagree........................... Disagree.................................... Undecided.................................. Agree... Strongly agree	01 02 03 04 05
18	I find my child(ren) enjoyable	Strongly disagree......................... Disagree.. Undecided.................................... Agree... Strongly agree	01 02 03 04 05

Socio-demography of healthy child

Questionnaire Code…………

Section: 1 Socio-demoghraphic information			
Qn	Questions	Responses	Code
1	Age of child (in year)	(………)year………..(month)	
2	Gender of Child	Male …………………………… Female…………………………	01 02
3	Age of mother	(………)year	
4	Mother education	No formal education…………. Primary level…………………… High school level……………….. Higher-secondary level……… Graduation/ Post graduation ……	01 02 03 04 05
5	Mother employment	Housewife ……………………… Teacher………………… Banker…………………………… Others………………………….....	01 02 03 04
6	Age of father	(………)year	
7	Father education	No formal education……………. Primary level………………… High school level……………….. High-secondary level…………… Graduation/ Post graduation…	01 02 03 04 05
8	Father employment	Service holder…………………… Farmer…………….. Teacher………………… Garments worker………….. Tailor …………………………...... Shopkeeper…………………… Rickshaw puller………… Driver………………………… Others……………………………	01 02 03 04 05 06 07 08 09
9	Living area	Rural Urban Sub Urban	01 02 03
10	Number of family members	………………………………….	01 02
11	Siblings	Yes……………………………. No……………………………	01` 02
12	Number of siblings (..)	Sister…………….. Brother…………………	01 02
13	What is the age of other child/children?	Sister…………year……..month Brother………year……..month	
14	Total income of your family	…………………………..	

15	What is the monthly expenditure of your family?	....	
16	Who is the earning member of the family	Father……………. Mother………….. Others ……………………	01 02 03
17	How much extra money is required purely for this child care	…………………………………	

Parental Stress Scale

QN	Questions	Response	Code
1	I am happy in my role as a parent	Strongly disagree.......................... Disagree..................................... Undecided................................. Agree... Strongly agree	01 02 03 04 05
2	There is little or nothing I wouldn't do for my child(ren) if it was necessary.	Strongly disagree........................... Disagree...................................... Undecided.................................. Agree... Strongly agree	01 02 03 04 05
3	Caring for my child(ren) sometimes takes more time and energy than I have to give.	Strongly disagree...................... Disagree...................................... Undecided.................................... Agree... Strongly agree	01 02 03 04 05
4	I sometimes worry whether I am doing enough for my child(ren).	Strongly disagree...................... Disagree........................... Undecided.......................... Agree...................................... Strongly agree............................	01 02 03 04 05
5	I feel close to my child(ren).	Strongly disagree......................... Disagree.. Undecided.................................. Agree............................ Strongly agree............................	01 02 03 04 05
6	I enjoy spending time with my child(ren).	Strongly disagree.......................... Disagree.................................... Undecided................................... Agree.................................... Strongly agree	01 02 03 04 05
7	My child(ren) is an important source of affection for me.	Strongly disagree.................... Disagree............................ Undecided............................ Agree...................................... Strongly agree..............................	01 02 03 04 05
8	Having child(ren) gives me a more	Strongly disagree......................	01

	certain and optimistic view for the future.	Disagree....................................... Undecided................................... Agree.. Strongly agree	02 03 04 05
9	The major source of stress in my life is my child(ren).	Strongly disagree......................... Disagree.................................... Undecided................................... Agree... Strongly agree.............................	01 02 03 04 05
10	Having child(ren) leaves little time and flexibility in my life.	Strongly disagree........................... Disagree....................................... Undecided......................... Agree... Strongly agree	01 02 03 04 05
11	Having child(ren) has been a financial burden.	Strongly disagree........................... Disagree....................................... Undecided..................................... Agree....................................... Strongly agree	01 02 03 04 05
12	It is difficult to balance different responsibilities because of my child(ren).	Strongly disagree......................... Disagree.......................... Undecided................................... Agree.. Strongly agree	01 02 03 04 05
13	The behaviour of my child(ren) is often embarrassing or stressful to me.	Strongly disagree.......................... Disagree.................................... Undecided................................. Agree.. Strongly agree	01 02 03 04 05
14	If I had it to do over again, I might decide not to have child(ren).	Strongly disagree............................. Disagree................................... Undecided..................................... Agree.. Strongly agree	01 02 03 04 05
15	I feel overwhelmed by the responsibility of being a parent.	Strongly disagree............................ Disagree.. Undecided................................. Agree.. Strongly agree	01 02 03 04 05
16	Having child(ren) has meant having too few choices and too little control over my life.	Strongly disagree............................ Disagree....................................... Undecided..................................... Agree..	01 02 03 04 05

		Strongly agree	
17	I am satisfied as a parent	Strongly disagree........................... Disagree..................................... Undecided.................................... Agree.. Strongly agree	01 02 03 04 05
18	I find my child(ren) enjoyable	Strongly disagree.......................... Disagree................................... Undecided................................. Agree................................ Strongly agree	01 02 03 04 05

প্রশ্নাবলীকোড..............

শাখাঃ১ সামাজিকওজনসংখ্যাতাত্তিক প্রশ্ন			
প্রশ্ন নং-	প্রশ্ন সমূহ	উত্তর	কোড
১	শিশুরবয়স	(...........) (বছর)	
২	শিশুর লিঙ্গ	পুরুষ.. নারী..	০১ ০২
৩	আপনার সন্তানের কোন ধরণের ''সেরেব্রাল পালসি''?	হেমি প্লেজিক............................. ডাইপ্লেজিক............................... মনোপ্লেজিক.............................. কোয়াড্রিপ্লেজিক..........................	০১ ০২ ০৩ ০৪
৪	মায়ের বয়স	(...........) (বছর)	
৫	মায়ের শিক্ষাগত যোগ্যতা	কোনবিদ্যালয়েপড়েননি....... প্রাথমিক সম্পন্ন .... মাধ্যমিক..................................... উচ্চমাধ্যমিক............................. স্নাতক/স্নাকোত্তর........................	০১ ০২ ০৩ ০৪ ০৫
৬	মায়ের পেশা	শিক্ষকতা.................................. ব্যাংকার....................................... ব্যবসায়ী..................................... গৃহিণী... অন্যান্য.......................................	০১ ০২ ০৩ ০৪ ০৫
৭	পিতার বয়স	(...........) (বছর)	

৮	পিতার শিক্ষাগত যোগ্যতা	কোনবিদ্যালয়েপড়েননি.......... প্রাথমিক সম্পন্ন.......................... মাধ্যমিক..................................... উচ্চমাধ্যমিক............................. স্নাতক/স্নাকোত্তর	০১ ০২ ০৩ ০৪ ০৫
৯	পিতারপেশা	চাকুরীজীবী .... কৃষক.. শিক্ষক... গার্মেন্টস ওয়ার্কার................................ টেইলার... দোকানদার...................................... রিকশাচালক............................. অন্যান্য.................	০১ ০২ ০৩ ০৪ ০৫ ০৬ ০৭ ০৮
১০	আবাসিক এলাকা	গ্রাম.. শহর .... উপশহর.....................................	০১ ০২ ০৩
১১	পরিবারের সদস্য সংখ্যা কতজন?	....	
১২	অন্য কোন ভাই-বোন আছে?	হ্যাঁ... না..	০১ ০২
১৩	ভাই-বোনদের সংখ্যা কত?	ভাই.. বোন...	
১৪	ভাই-বোনদের বয়স কত?	ভাই.................বছর/মাস .... বোন..............বছর/ মাস...........	
১৫	তাদের কারও মধ্যে বিকলঙ্গতা আছে?	হ্যাঁ... না..	০১ ০২
শাখাঃ২ সেবাগ্রহণেরজন্যআপনিযেসবজায়গায়গিয়েছেন			
১	আপনিকিআপনারসন্তানেররোগেরনামসম্পর্কেজানেন?	হ্যাঁ.. না..	০১ ০২
২	রোগটি কতদিন আগে ধরা পরে ?	শিশুর বয়স তখন ...বছর/ মাস	
৩	রোগটি কে নির্ণয় করেন?	গ্রাম্য ডাক্তার.................... কবিরাজ নিবন্ধনকৃত চিকিৎসক............. শিশু বিশেষজ্ঞ.................। থেরাপিস্ট.............. অন্যান্য..............	০১ ০২ ০৩ ০৪ ০৫ ০৬

৪	কখন আপনি শিশুর চিকিৎসা শুরু করেন?	রোগ ধরা পরার সাথে সাথে .... রোগ নির্ণয়ের পূর্বে .... অন্যান্য.............	০১ ০২ ০৩
৫	এই রোগ নির্ণয় এর পর প্রথমে আপনারা এই রোগের চিকিৎসার জন্যে কোথায় গিয়েছিলেন?	কোন চিকিৎসা নেননি/ কবিরাজ এর কাছে........ গ্রাম্য ডাক্তারের কাছে/স্থানীয়ফার্মেসী... কমিউনিটি ক্লিনিক/ থানা স্বাস্থ্য কমপ্লেক্সে........... জেলা স্বাস্থ্য কমপ্লেক্সে........... মেডিকেল কলেজ/ হাসপাতালে......... সরকারি হাসপাতালে........... বেসরকারি হাসপাতালে........... বিশেষ শিশু কল্যাণ কেন্দ্র.........	০১ ০২ ০৩ ০৪ ০৫ ০৬ ০৭ ০৮
৬	সিআরপি তে আসার আগে আপনার শিশু কি কখনও ফিজিওথেরাপি/ অকুপেশনাল/ স্পীচ এবং ল্যাংগুয়েজ থেরাপি নিয়েছে?	হ্যাঁ.............. না.........	০১ ০২
৭	যদি হ্যাঁ , কোথায়?	....	
৮	সিআরপি তে আসার আগে আপনি কোথায় এত দিন যাবত চিকিৎসা চালিয়ে গেছেন?	কোন চিকিৎসা নেননি/ কবিরাজ এর কাছে................. গ্রাম্য ডাক্তারের কাছে/স্থানীয় ফার্মেসী... কমিউনিটি ক্লিনিক/ থানা স্বাস্থ্য কমপ্লেক্সে............ জেলা স্বাস্থ্য কমপ্লেক্সে............ মেডিকেল কলেজ/ হাসপাতালে......... সরকারি হাসপাতালে............ বেসরকারি হাসপাতালে............ বিশেষ শিশু কল্যাণ কেন্দ্র.........	০১ ০২ ০৩ ০৪ ০৫ ০৬ ০৭ ০৮
৯	আপনি সেখানে কত দিন যাবত চিকিৎসা নিয়েছেন?	....	
	শাখাঃ সেবাদান কারীর তথ্য		
১	শিশুর দেখাশুনা কে করে?	মাতা.............. পিতা................. অন্যান্য.....	০১ ০২ ০৩
২	শিশুর দেখাশুনার জন্য দৈনিক কত ঘণ্টা সময় ব্যয় করতে হয়?	....	

৩	শিশুর পরিচর্যা কি আপনার অন্য কোন সাংসারিক কাজ ব্যহত করে?	হ্যাঁ................. না..............	০১ ০২
৪	আপনি কি মনে করেন শিশুর পরিচর্যা করতে গিয়ে আপনি আপনার অন্য সাংসারিক কাজ করতে পারেননা?	হ্যাঁ................. না..............	০১ ০২
৫	যদি অন্য সন্তান থাকে, আপনি কি মনে করেন এই শিশুর কারনে আপনি আপনার অন্য সন্তান কে যথেষ্ট সময় দিতে পারেন না?	হ্যাঁ................. না..............	০১ ০২
৬	যদি অন্য সন্তান না থাকে, আপনি কি অন্য সন্তান নেয়ার পরিকল্পনা করছেন?	হ্যাঁ................. না..............	০১ ০২
৭	আপনি কি মনে করেন আরও একটি সন্তান নিলে ওই সন্তানের ও এই একই সমস্যা হতে পারে ?	হ্যাঁ................. না..............	০১ ০২
৮	যদি চাকরি করে থাকেন, আপনার এই শিশুর রোগ এর কারনে কি আপনার চাকরী ছাড়তে হয়েছে?	হ্যাঁ................. না..............	০১ ০২
৯	আপনি যদি এখনও চাকরী করে থাকন তাহলে কি আপনার চাকরী ছাড়ার প্রয়োজন হতে পারে?	হ্যাঁ................. না..............	০১ ০২
শাখাঃ ৪ অর্থনৈতিক তথ্য			
১	পরিবারের মাসিকআয়	....	
২	আপনার পরিবারের মাসিক ব্যয় কত?	....	
৩	পরিবারের উপার্জন কারী কে ?	বাবা............................. মা.......................... অন্যান্য.....	০১ ০২ ০৩
৪	আপনার এইশিশুটির জন্য কি অতিরিক্ত ব্যয় হয়?	হ্যাঁ .... না..........................	০১ ০২
৫	আপনারএইশিশুটির জন্যমাসেঠিক কতটা অতিরিক্ত খরচ হয়?	....	
৬	এই শিশুটিরজন্য খরচেরটাকাকোথাথেকেআসে ?	সঞ্চিত আয় থেকে.......................... পরিবারের সাহায্য থেকে................. চাকরী থেকে...................................	০১ ০২ ০৩

		বন্ধুদের সাহায্য থেকে........................ সরকারের সহয়তায় বা অন্য কোন সংস্থা জমি বিক্রি করে বা অন্য কিছু বিক্রি করে. ধার করে............................ অন্যান্য...	০৪ ০৫ ০৬ ০৭ ০৮
প্যারেন্টাল স্ট্রেস স্কেল			
০১	আপনিকিমাহিসেবেএইসন্তানকে নিয়েখুশি ?	একবারেই একমত নই একমত নই বুঝতে পারতেছি না একমত একবারেই একমত	০১ ০২ ০৩ ০৪ ০৫
০২	আমি আমার শিশুটিরজন্য যেকোনোকিছুইকরতে পারি ।	একবারেই একমত নই একমত নই বুঝতে পারতেছি না একমত একবারেই একমত	০১ ০২ ০৩ ০৪ ০৫
০৩	আমার শিশুর যত্নের জন্য আমি যতটুকু পারি তার চেয়ে মাঝে মাঝে অনেক বেশি সময় ও শক্তির প্রয়োজন হয়।	একবারেই একমত নই একমত নই বুঝতে পারতেছি না একমত একবারেই একমত	০১ ০২ ০৩ ০৪ ০৫
০৪	আমি মাঝে মাঝে চিন্তা করি আমি আমার শিশুটির জন্য যথেষ্ট করতে পারিকিনা...	একবারেই একমত নই একমত নই বুঝতে পারতেছি না একমত একবারেই একমত	০১ ০২ ০৩ ০৪ ০৫
0৫	আমার সন্তানের সাথেআমারবন্ধনটাখুব শক্ত।	একবারেই একমত নই একমত নই বুঝতে পারতেছি না একমত একবারেই একমত	০১ ০২ ০৩ ০৪ ০৫
০৬	আমি আমার শিশুর সাথে সময় কাটাতে আনন্দ পাই	একবারেই একমত নই একমত নই বুঝতে পারতেছি না একমত একবারেই একমত	০১ ০২ ০৩ ০৪ ০৫

০৭	আমার শিশু আমার ভালবাসার একটি গুরুত্বপূর্ণ উৎস	একবারেই একমত নই একমত নই বুঝতে পারতেছি না একমত একবারেই একমত	০১ ০২ ০৩ ০৪ ০৫
০৮	এই শিশুটি আমার ভবিষ্যতের আশা।	একবারেই একমত নই একমত নই বুঝতে পারতেছি না একমত একবারেই একমত	০১ ০২ ০৩ ০৪ ০৫
০৯	আমার শিশুই আমার জীবনের সবচেয়ে বড় দুশ্চিন্তা	একবারেই একমত নই একমত নই বুঝতে পারতেছি না একমত একবারেই একমত	০১ ০২ ০৩ ০৪ ০৫
১০	এই শিশুর জন্য আমার জীবনের সময় ও সুযোগ বলে কিছু নেই ।	একবারেই একমত নই একমত নই বুঝতে পারতেছি না একমত একবারেই একমত	০১ ০২ ০৩ ০৪ ০৫
১১	আমার শিশুটি আমার জন্য অর্থনৈতিক চিন্তার কারন।	একবারেই একমত নই একমত নই বুঝতে পারতেছি না একমত একবারেই একমত	০১ ০২ ০৩ ০৪ ০৫
১২	আমার শিশুর জন্য আমার অন্য সব দায়িত্ব পালন করা কঠিন।	একবারেই একমত নই একমত নই বুঝতে পারতেছি না একমত একবারেই একমত	০১ ০২ ০৩ ০৪ ০৫
১৩	এই শিশুটির আচরনমাঝে মাঝে আমার জন্য বিব্রতকর এবং দুশ্চিন্তারকারন।	একবারেই একমত নই একমত নই বুঝতে পারতেছি না একমত একবারেই একমত	০১ ০২ ০৩ ০৪ ০৫
১৪	যদি আমার এই যন্ত্রণা আবার পেতে হয় তাহলে আমি কখনও ই আবার সন্তান নিতে চাই না ।	একবারেই একমত নই একমত নই বুঝতে পারতেছি না	০১ ০২ ০৩

		একমত একবারেই একমত	০৪ ০৫
১৫	এই শিশুর জন্য আমি সব সময় ব্যতিব্যস্ত আর কিছুই করতে পারি না।	একবারেই একমত নই একমত নই বুঝতে পারতেছি না একমত একবারেই একমত	০১ ০২ ০৩ ০৪ ০৫
১৬	এই শিশুকে কারনে আমি আমার নিজের জীবন সম্পর্কে ভাবতেও পারি না	একবারেই একমত নই একমত নই বুঝতে পারতেছি না একমত একবারেই একমত	০১ ০২ ০৩ ০৪ ০৫
১৭	আমি মা হিসেবে সন্তুষ্ট ।	একবারেই একমত নই একমত নই বুঝতে পারতেছি না একমত একবারেই একমত	০১ ০২ ০৩ ০৪ ০৫
১৮	আমি আমার শিশুর সাথে থাকতে পছন্দ করি।	একবারেই একমত নই একমত নই বুঝতে পারতেছি না একমত একবারেই একমত	০১ ০২ ০৩ ০৪ ০৫

প্রশ্ন নং-	প্রশ্ন সমূহ	উত্তর	কোড
শাখাঃ১ সামাজিকওজনসংখ্যাতাত্তিক প্রশ্ন			
১	শিশুরবয়স	(...........) (বছর)	
২	শিশুর লিঙ্গ	পুরুষ.. নারী..	০১ ০২
৩	মায়ের বয়স	(...........) (বছর)	
৪	মায়ের শিক্ষাগত যোগ্যতা	কোনবিদ্যালয়েপড়েননি....... প্রাথমিক সম্পন্ন .... মাধ্যমিক..................................... উচ্চমাধ্যমিক............................ স্নাতক/স্নাকোত্তর........................	০১ ০২ ০৩ ০৪ ০৫

৫	মায়ের পেশা	শিক্ষকতা................................ ব্যাংকার..................................... ব্যবসায়ী................................... গৃহিণী...................................... অন্যান্য....................................	০১ ০২ ০৩ ০৪ ০৫
৬	পিতার বয়স	(...........) (বছর)	
৭	পিতার শিক্ষাগত যোগ্যতা	কোনবিদ্যালয়েপড়েননি.......... প্রাথমিক সম্পন্ন......................... মাধ্যমিক.................................... উচ্চমাধ্যমিক............................ স্নাতক/স্নাকোত্তর	০১ ০২ ০৩ ০৪ ০৫
৮	পিতারপেশা	চাকুরীজীবী .... কৃষক... শিক্ষক... গার্মেন্টস ওয়ার্কার............................... টেইলার... . দোকানদার..................................... রিকশাচালক............................ অন্যান্য.................	০১ ০২ ০৩ ০৪ ০৫ ০৬ ০৭ ০৮
৯	আবাসিক এলাকা	গ্রাম... শহর .... উপশহর....................................	০১ ০২ ০৩
১০	পরিবারের সদস্য সংখ্যা কতজন?	....	
১১	অন্য কোন ভাই-বোন আছে?	হ্যাঁ.. না..	০১ ০২
১ ২	ভাই-বোনদের সংখ্যা কত?	ভাই.. বোন...	
১ ৩	ভাই-বোনদের বয়স কত?	ভাই.................বছর/মাস .... বোন..............বছর/ মাস...........	
১ ৪	পরিবারের মাসিকআয়	....	
	আপনার পরিবারের মাসিক ব্যয় কত?	....	

১ ৫		....	
১৬	পরিবারের উপার্জন কারী কে ?	বাবা............................. মা.......................... অন্যান্য.....	
১৭	এইশিশুটিরজন্যমাসেঠিককতটাকাখরচহয়?		
শাখাঃ ২ প্যারেন্টাল স্ট্রেস স্কেল			
০১	আপনিকিমাহিসেবেএইসন্তানকে নিয়েখুশি ?	একবারেই একমত নই একমত নই বুঝতে পারতেছি না একমত একবারেই একমত	০১ ০২ ০৩ ০৪ ০৫
০২	আমি আমার শিশুটিরজন্য যেকোনোকিছুইকরতে পারি ।	একবারেই একমত নই একমত নই বুঝতে পারতেছি না একমত একবারেই একমত	০১ ০২ ০৩ ০৪ ০৫
০৩	আমার শিশুর যত্নের জন্য আমি যতটুকু পারি তার চেয়ে মাঝে মাঝে অনেক বেশি সময় ও শক্তির প্রয়োজন হয়।	একবারেই একমত নই একমত নই বুঝতে পারতেছি না একমত একবারেই একমত	০১ ০২ ০৩ ০৪ ০৫
০৪	আমি মাঝে মাঝে চিন্তা করি আমি আমার শিশুটির জন্য যথেষ্ট করতে পারিকিনা...	একবারেই একমত নই একমত নই বুঝতে পারতেছি না একমত একবারেই একমত	০১ ০২ ০৩ ০৪ ০৫
0৫	আমার সন্তানের সাথেআমারবন্ধনটাখুব শক্ত।	একবারেই একমত নই একমত নই বুঝতে পারতেছি না একমত একবারেই একমত	০১ ০২ ০৩ ০৪ ০৫
০৬	আমি আমার শিশুর সাথে সময় কাটাতে আনন্দ পাই	একবারেই একমত নই একমত নই বুঝতে পারতেছি না একমত একবারেই একমত	০১ ০২ ০৩ ০৪ ০৫
০৭	আমার শিশু আমার ভালবাসার একটি	একবারেই একমত নই	০১

	গুরুত্বপূর্ণ উৎস	একমত নই বুঝতে পারতেছি না একমত একবারেই একমত	০২ ০৩ ০৪ ০৫
০৮	এই শিশুটি আমার ভবিষ্যতের আশা ।	একবারেই একমত নই একমত নই বুঝতে পারতেছি না একমত একবারেই একমত	০১ ০২ ০৩ ০৪ ০৫
০৯	আমার শিশুই আমার জীবনের সবচেয়ে বড় দুশ্চিন্তা	একবারেই একমত নই একমত নই বুঝতে পারতেছি না একমত একবারেই একমত	০১ ০২ ০৩ ০৪ ০৫
১০	এই শিশুর জন্য আমার জীবনের সময় ও সুযোগ বলে কিছু নেই ।	একবারেই একমত নই একমত নই বুঝতে পারতেছি না একমত একবারেই একমত	০১ ০২ ০৩ ০৪ ০৫
১১	আমার শিশুটি আমার জন্য অর্থনৈতিক চিন্তার কারন।	একবারেই একমত নই একমত নই বুঝতে পারতেছি না একমত একবারেই একমত	০১ ০২ ০৩ ০৪ ০৫
১২	আমার শিশুর জন্য আমার অন্য সব দায়িত্ব পালন করা কঠিন।	একবারেই একমত নই একমত নই বুঝতে পারতেছি না একমত একবারেই একমত	০১ ০২ ০৩ ০৪ ০৫
১৩	এই শিশুটির আচরনমাঝে মাঝে আমার জন্য বিব্রতকর এবং দুশ্চিন্তারকারন।	একবারেই একমত নই একমত নই বুঝতে পারতেছি না একমত একবারেই একমত	০১ ০২ ০৩ ০৪ ০৫
১৪	যদি আমার এই যন্ত্রণা আবার পেতে হয় তাহলে আমি কখনও ই আবার সন্তান নিতে চাই না ।	একবারেই একমত নই একমত নই বুঝতে পারতেছি না একমত	০১ ০২ ০৩ ০৪

		একবারেই একমত	০৫
১৫	এই শিশুর জন্য আমি সব সময় ব্যতিব্যস্ত আর কিছুই করতে পারি না।	একবারেই একমত নই একমত নই বুঝতে পারতেছি না একমত একবারেই একমত	০১ ০২ ০৩ ০৪ ০৫
১৬	এই শিশুকে কারনে আমি আমার নিজের জীবন সম্পর্কে ভাবতেও পারি না	একবারেই একমত নই একমত নই বুঝতে পারতেছি না একমত একবারেই একমত	০১ ০২ ০৩ ০৪ ০৫
১৭	আমি মা হিসেবে সন্তুষ্ট ।	একবারেই একমত নই একমত নই বুঝতে পারতেছি না একমত একবারেই একমত	০১ ০২ ০৩ ০৪ ০৫
১৮	আমি আমার শিশুর সাথে থাকতে পছন্দ করি।	একবারেই একমত নই একমত নই বুঝতে পারতেছি না একমত একবারেই একমত	০১ ০২ ০৩ ০৪ ০৫

April 10, 2017

The Head

Department of Physiotherapy
Center for the Rehabilitation of the paralysed (CRP)
CRP, Chapain, Savar, Dhaka-1343.

Through: Head, Department of Physiotherapy, BHPI.

Subject: Application for permission for data collection.

Dear Sir,

With due respect and humble submission to state that I am Fatema Tuj Johora, student of 4th Professional B.Sc. in Physiotherapy at Bangladesh Health Professions Institute (BHPI). The ethical board of BHPI has approved my research project entitled on **"Economical Burden and Stress on Families of Children with Cerebral Palsy".** To conduct this research, I want to collect data from the children with cerebral palsy who are admitted in Paediatric unit at CRP. So, I need your permission for data collection from the children with cerebral palsy from Paediatric unit at CRP. I would like to assure that anything of my study will not be harmful for the participants.

I therefore, pray and hope that you would be kind enough to give me the permission to make this research project successful.

Sincerely

Fatema tuj johora

Fatema Tuj Johora

4th Professional B.Sc. in Physiotherapy
Class Roll-33, Session: 2012-2013
Bangladesh Health Professions Institute (BHPI)
(An academic Institute of CRP)
CRP, Chapain, Savar, Dhaka-1343.

Recommended & Forwarded
16/04/17
Md. Obaidul Haque
Associate Professor & Head of the Department
Department of Physiotherapy
Bangladesh Health Professions Institute (BHPI)
CRP, Chapain, Savar, Dhaka-1343

Approved
Contact with Shahnaz Sultana as a counter part of data collection process.
18/04/17
Mohammad Anwar Hossain
Associate Professor
Head of Physiotherapy Dept.
CRP, Chapain, Savar, Dhaka-1343

April 8, 2017

The Head

Department of Physiotherapy
Bangladesh Health Professions Institute (BHPI),
CRP, Chapain, Savar, Dhaka-1343.

Subject: Application for permission for data collection.

Dear Sir,

With due respect and humble submission to state that I am Fatema Tuj Johora, student of 4th Professional B.Sc. in Physiotherapy at Bangladesh Health Professions Institute (BHPI). The ethical board of BHPI has approved my research project entitled on **"Economical Burden and Stress on Families of Children with Cerebral Palsy".** To conduct this research, I want to collect data from a community school name Hanada scholars school in order to compare normal children with children with cerebral palsy. So, I need your permission for data collection from the community. I would like to assure that anything of my study will not be harmful for the participants.

I therefore, pray and hope that you would be kind enough to give me the permission to make this research project successful.

Sincerely
Fatema tuj Johora

Fatema Tuj Johora

4th Professional B.Sc. in Physiotherapy
Class Roll-33, Session: 2012-2013
Bangladesh Health Professions Institute (BHPI)
(An academic Institute of CRP)
CRP, Chapain, Savar, Dhaka-1343.

Firoz Ahmed Mamin
BSPT (DU), MSc in Clinical Neuroscience (London)
Assistant Professor
Department of Physiotherapy
BHPI, CRP Savar Dhaka

Allowed
09/04/17
Md. Obaidul Haque
Associate Professor & Head of the Department
Department of Physiotherapy
Bangladesh Health Professions Institute (BHPI)
CRP, Chapain, Savar, Dhaka-1343

বাংলাদেশ হেল্থ প্রফেশন্স ইনষ্টিটিউট (বিএইচপিআই)
BANGLADESH HEALTH PROFESSIONS INSTITUTE (BHPI)
(The Academic Institute of CRP)

Ref: CRP-BHPI/IRB/04/17/104 *Date:* 15/04/2017

To
Fatema tuj johora
B.Sc in Physiotherapy
Session: 2012-2013, Student ID 112120034
BHPI, CRP, Savar, Dhaka-1343, Bangladesh

Subject: "Economical Burden and Parental Stress on Families of Children with Cerebral Palsy".

Dear Fatema tuj johora,

The Institutional Review Board (IRB) of BHPI has reviewed and discussed your application on 16/08/2016 to conduct the above mentioned thesis, with yourself, as the Principal investigator. The Following documents have been reviewed and approved:

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

Since the study involves Parental stress scale, a self-administered socio-demographic and Cost analysis questionnaire that takes 15 to 20 minutes and have no likelihood of any harm to the participants. The members of the Ethics committee have approved the study to be conducted in the presented form at the meeting held at 09:00 AM on August 17, 2016 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,

Millathossain

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

CRP-Chapain, Savar, Dhaka-1343. Tel: 02-7745464-5, 7741404 , Fax: 02-7745069,
Email: contact@crp-bangladesh.org, www.crp-bangladesh.org