

Stress Level of Mothers of the Children with Cerebral Palsy

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SUPERVISOR'S STATEMENT

As the supervisor of Farjana Akhter's thesis work, I certify that I consider her thesis "Stress Level of Mother of the Children with Cerebral Palsy" to be suitable for examination.



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Declaration Form

This work has not previously been accepted in substance for any degree and is not concurrently submitted in candidature for any degree.

This dissertation is being submitted in partial fulfillment of the requirements for the degree of MSc in Rehabilitation Science.

This dissertation is the result of my own independent work/investigation, except where otherwise stated. Other sources are acknowledged by giving explicit references.

A Bibliography is appended.

I confirm that if anything identified in my work that I have done plagiarism or any form of cheating that will directly awarded me fail and I am subject to disciplinary actions of authority.

I confirm that the electronic copy is identical to the bound copy of the Thesis.

Signature.....

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List of Acronyms

- APA:** American Psychological Association
BHPI: Bangladesh Health Professions Institute
BMRC: Bangladesh Medical Research Council
CRP: Centre for the Rehabilitation of the Paralysed
CP: Cerebral Palsy
LBP: Low Back Pain
NGO: Non-Government Organization
PSS: Parental Stress Scale
SPSS: Statistical Package for Social Science
WHO: World Health Organization

Abstract

Mother of children with Cerebral Palsy (CP) plays an essential role in the successful rehabilitation of their children which may affect their mental health. The aim of this study is to find out the level of stress of mothers of children with CP. The objectives are to find out socio-demographic characteristics, level of stress of the mothers, to find out the association between socio-demographic characteristics and severity of stress of mothers and to identify the information about their social participation. A cross sectional study was conducted in the pediatric unit of Centre for the Rehabilitation of the Paralyzed (CRP) at Savar. 111 participants were included in this study. Socio-demographic questionnaire, Parental Stress Scale (PSS) and Questions about social integration was used for data collection and analysis was done by using Statistical Package for Social Science (SPSS) version 24. In this study, it was found that most of the participants' (51.1%) were 24-28 years, 36.9% (n=41) had education up to secondary school, 96.4% (n=107) were married, 38.7% (n=43) came from semi urban areas and 36.0% (n=40) came from rural areas. 75.7% (n=84) took care their children for 11 hours and above, 45.9% (n=51) had two child and 72.9% (n=81) came from middle socio-economic status. In case of Stress level 8.1% had low, 76.5% had high and 14.4% had extreme level of stress. There were significant association between living area ($p > .013$) and socioeconomic status ($p > .026$) with level of stress of the participants. 57.7% participants said they can not attend in social functions, 63.1% claimed no accessibility in shopping mall, 79.3% said lack of option in public transport and 72.1% felt isolated themselves from the society.

In conclusion, it seems that having a CP child lead to maternal stress so, to improve rehabilitation processes psychological support for mothers is needed.

Key Words: *Cerebral Palsy, Mothers' Stress, Social Integration*

1. Background

Bangladesh is one of the world's most densely populated countries. The population of Bangladesh is about 160 million. A number of total people with disability have been registered in Bangladesh was 15,93,070 in 2018 according to the National Taskforce on Disabilities-friendly Disaster Management Affairs. Estimates show that people are living with a disability in Bangladesh are 10% of the population which is 16 million. Every year there are a lot of babies born with disabilities, due to many poor conditions of the country, for example poor maternal health care, lack of nutrition and lack of education. According to Disability in Bangladesh (2014) disabilities in children appraised at 6% below 18 years and the prevalence at about 14% for the age group above eighteen years, or corresponding to children with disabilities 3.4 million and adults with disabilities 10.2 million. There are many conditions of children with disabilities in Bangladesh, such as Autism spectrum disorder, cerebral palsy, Down syndrome, deaf-blindness, intellectual disability, hearing impairment, physical impairment, speech impairment, visual impairment and multiple disability. A study showed that prevalence of cerebral palsy (CP) in rural Bangladesh is 3.4 per 1000 children. There are an estimated that the children with cerebral palsy in Bangladesh are total 233 514 in amount. The preventable risk factors are in majority group. The opportunities for early intervention limited by delayed diagnosis of cerebral palsy. The existing services for children with CP in rural Bangladesh are very limited (khandakar et al.,2018). Having a child with CP has an undesirable effect on a mother's daily life. These mothers dedicated a huge amount of period to taking care of their child and very few periods for their self-care, productive activities, leisure and social participation. They are stigmatized by the society due to having children with special needs. This rises their stress level which make them demotivated to take treatment or intervention of the child for long. Another study finding showed the causes of cerebral palsy among mothers had different perceptions and most of them related to spiritual motives. Mothers of CP child suffer into various physical, emotional, financial, marital and social challenges (Menlah et al., 2020). It has been defined as stressful and challenging for look after or caring for a child with cerebral palsy, particularly for mothers because mothers often times have a tendency to be the first caregivers of children with cerebral

palsy. In other studies, it was stated that all aspects of the caregiver's life including, psychological, mental, physical, spiritual and economical affected by the stress of caring for children with disability such as cerebral palsy (Gupta & Kaur, 2010; Hubert, 2010). other studies also reported similarly findings of how stress increased by caring for children with cerebral palsy (Nurullah,2013). Moreover, the quality of life for both the child and the caregiver has overwhelming consequences on caregivers leading to declined (Dambi et al., 2015). A study claimed that birth of a CP child is one of the unfortunate events in the life of any parents. This incident could impair their mental health (Rezvani,2014). Hung *et al.* (2010) said the first reactions of parents after a disability diagnosis of their children are sense of injustice, resentment against fate, blaming each other. Another study said parents of such children may suffer from different conditions such as depression, anxiety, anger, fear, shame and desire to die (Rezvani,2014). According to a study it was found that the high level of stress is tolerated by the mothers of children with different levels of disability (Sajedi *et al.*, 2010). According to Zanon and Batista (2012) the need of constant assistance for children with CP can make their mothers become stressed. Mother's wellbeing depends on the child's level of impairment, care giving demand, and family structure.

Another study showed that mothers of children with CP seem to have been neglected by the health care system and also facing many difficulties to social participation (Dehghan et al. 2015). A family with the children with CP face financial difficulties to bear their life long treatment and equipment. A study in Bangladesh reported that financial needs were the highest priority in the family with CP child (Nuri et al. 2018). The mothers of children with CP cannot have enough time for their own as because of they have to give much more time for looking after their children with CP. There is some functional limitation are present in Children with CP which vary their severity. So, they become fully dependent on their first care giver specially on their mother. They are special need children so those mothers have to take care of their children specially which need extra time and more energy. These mothers become stressed because of their children's future at the same time they face various social stigma. A study in India showed that mothers get less support or no support from their family members, they face social negative attitude, financial burden and limitation of social participation (Vadivelan et al., 2020). The rejection from people about the children with disability and the suffering many problems from surrounding different environments with showed by the looks, comments and attitudes are facing by the mother and for having generated

children with disability, for having the inherent emotions and feelings they still experience the feeling of guilt. Mothers expectations towards maternity goal failed to meet for having children with disability. She often pushes her away from family members and from her own children because of showing pain, sadness and worry in her speech. They experience questioning herself about the reason why this happened, a time of uncertainty, of feelings of trouble and fear in face of the threat perceived in the child's impossibilities (Barbosa et al., 2008). It seems that when mothers are overburdened by the demands of care giving, earning a living, and other responsibilities it has been explained that children of special need and mothers are at risk of stress-related problems.

Everyone wants fit and intelligent children who will do well in the competitive society they live in. due to taking more responsibility or care to their children than the other family members, mothers often feel guilty which caused by the birth of a disabled child a family stressor (khayatzaheh et al. 2013 and Sajedi et al., 2010). CP Children cannot perform independently. In these situations, to perform activities of daily living for a long-time child with CP need assistance and care (Altinda et al. 2007). Mother of children with CP require more attention and longer duration of care, these excessive responsibilities can negatively affect their physical, psychological and social health (Kumari and Joseph, 2014, Marron et.al., 2013 and Al Gamal, 2013)._Mother of children with CP suffers from depression, grief, disbelief, fear, hopelessness and feelings of inability to cope for their children with long-term disability (Al-Gamal, 2013). A study carried out in Bangladesh reported by Mubarak and colleagues that the rate of morbidity is of psychiatric is 41.8% in mothers of children with CP (Eker and Tuzun, 2004 and Gleen et al. 2009). Children with CP often suffer from sleep troubles, which affect their caregiver's quality of sleep as well (Marx et. al., 2011). The higher levels of stress have relation with poor sleep quality. Another study reported that the mothers who having cerebral palsy child were high rates in musculoskeletal pain (62.5%) and Low Back Pain (LBP) (42%) (Kaya et al. 2010). Mental health problem has a significant adverse effect on the physical and social health of individuals (Saywer et al. 2011). Psychological distress, depressed mood was associated with transition to chronic LBP (Kaya et al. 2010).

Moreover, mothers have to manage household activities, family relationships, caring for other children at the same time as caring for a disabled child for long-time. As a

result, there is an overload on the mother which creates stress. Sleep and behavior difficulties of a child with disabilities have a significant impact on mother psychological stress level because of everyday caring for their children (Sloper and Turner, 1993). Factors of stress relate to the process of many child-related factors and mothers' related factors and various sources (Ketelaar et al., 2008). According to these circumstances and all the above reasons the researcher wanted to conduct this study.

2. Justification

This study focused on the stress level of the mother of the children with cerebral palsy which will help to pay attention towards the mothers' stress level and arrange stress management program according to the stress level. These programs will help the mothers to relief from the stress and motivate themselves to take interventions for their children. It will help the different health professionals to know about mothers' stress level, so they can consider during treatment sessions. Mother has important roles in better prognosis of children with CP. It is very important to maintain mothers' mental and physical health during care giving. If they are provided treatment through a stress management programs, they will be free from stress and they can be ensured a better quality of life. Healthcare professionals should focus interventions and preventive strategies on the children and the mothers' (ketelaar et al., 2008). A study reported that the stress of dealing with special needs children or children with disabilities is a chief risk factor for the development of physical and psychosocial difficulties in both the affected children and family members, especially it has huge impact on the mothers of those children. Many health professionals have achieved better child functioning because they have focused interventions for the mothers (Manual et al., 2012).

A mother is the first care giver of a child. The mother of a child with CP work hard to rare and care her child. Sometimes they don't get supports from family, society and environment which cause increase their stress. Mother will experience a higher level of stress and anxiety because of the mother's central role in family life and responsibilities for childcare (Borzoo *et al.*, 2014). That effect on their motivation of special caring the special need child. This study will help to pay attention to the health care professional, health care service provider organizations, the family of the CP children and their community about the stress level of the mothers. Mothers stress level are directly related to better outcome or result of the children with CP through interventions.

3. Research Question:

What is the stress level of mothers of children with Cerebral palsy?

4. Conceptual framework:

Independent variable

Dependent variable

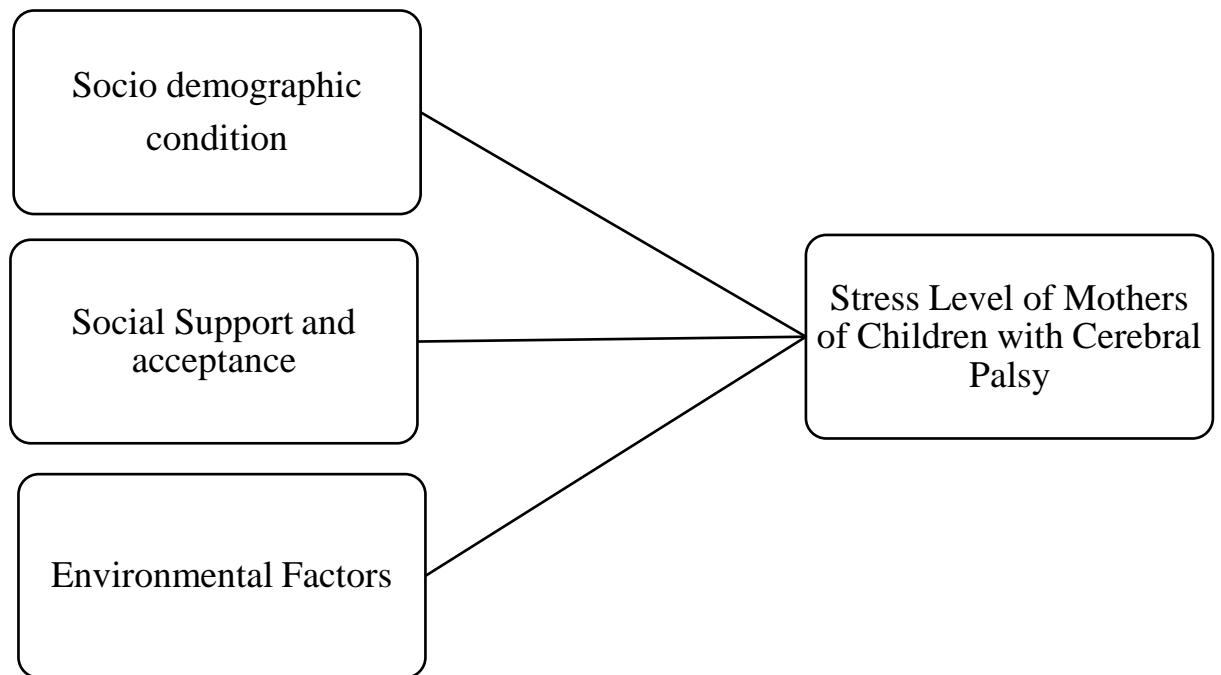


Figure 1: Factors of stress

Socio demographic condition:

Socio demographic condition include the name, age, gender, living area, education, professions, income source etc.

Social support and acceptance:

A mother is the first care giver of a child. During the child rearing time that mother needs social support and positive attitude towards the child especially when they have a child with special needs. This is very hard for a mother to maintain or care a child without social support and acceptance. Supports are like working support, mentally and economically supports, positive attitudes etc.

Environmental factors:

Environmental factors include living area, social environment, accessibility etc. These factors also effect on the care giving of a child with cerebral palsy.

5. Objectives of the study

5.1 General objective

To find out the stress level of mothers of children with Cerebral palsy.

5.2 Specific objectives

1. To identify the common socio- demographic picture of mothers of children with CP.
2. To find out the severity of stress level of mothers of children with Cerebral palsy.
3. To identify the association between socio- demographic characteristics and level of stress of mothers with CP.
4. To find out the information about their social participation.

In Bangladesh, the diagnosis of CP is significantly delayed in spite of being the high burden of CP and also minimizes the opportunities for early intervention. The services are not available and are limited too in some cases. There are preventable risk factors in the majority of the children. The prevalence of cerebral palsy (CP) is 3.4 per 1000 children in rural Bangladesh. The numeric figure of children with CP in Bangladesh is 233 514 (estimated). Among the children majority have potentially preventable risk factors. There are limited opportunities for early interventions also the Diagnosis of CP is delayed due to several factors. The existing healthcare services for children with CP in rural Bangladesh is not enough. (khandakar et. al.,2018). According to a traditional estimation there are 1-2% of all babies are born with some configuration of cerebral palsy, in a country with more than 161 million populations. Cerebral palsy is a condition between the brain and muscles which interrupts the nerve signals and leads to the problem with movement of limbs, posture and co-ordination of the physical structure of the children as they grow up. On a recent (2020) population-based studies of Center for Disease control and prevention, has shown that, there are nearly 1-4 CP child. According to CDC (2020) recent population-based studies from around the world report prevalence estimates of CP ranging from 1 to nearly 4 per 1,000 live births or per 1,000 children. The incidence of CP is higher for children born preterm or at low birthweight.

National Institute of Neurological Disorder and Stroke (2013) showed that Cerebral palsy is caused by abnormal development of part of the brain or by damage to parts of the brain that control movement. This damage can happen before, during, or shortly after birth. Still in many cases, the actual reason of cerebral palsy is unknown. Probable causes include genetic problems, congenital or by birth brain malformations, maternal infections or fevers during pregnancy, or fetal injury at womb, for example. There are some kind of brain damage or injury may cause its some symptoms these are: the brain damage by damaging white matter of the brain, brain developing abnormally, bleeding within brain by any internal or external injury, severe lack of oxygen in the brain at womb.

According to Newman, T. (2017), there are some medical conditions or moments which may take place during pregnancy and delivery and can be the catalyst of increase a baby's risk of being born with cerebral palsy. These caused by: premature birth, low birthweight and birth of twin or more than one baby at a time, contaminations in pregnancy period, blood groups incompatibility between mother and fetus and exposure to poisonous substances, mothers who have thyroid problems, intellectual difficulties, excess protein in the urine and convulsion. Mothers who have any of these conditions are tend to be have a child with CP.

There are also some medical situations during child birth period or labor and delivery, and instantly after delivery that turn as threatening signs for an increased risk of CP. Some signs contain: presents of breech position, labor and delivery complication, less Apgar score, Jaundice, seizures or convulsion.

A child who have the condition of cerebral palsy may chance to have muscle problems and movement difficulties and also problems in tone of limbs muscle. A person's automatic capability to tighten and relax muscle when required is caused by muscle tone. Features are consisting: muscles overdeveloping or underdeveloped condition, stiff or floppy movements may present, coordination and balance difficulties which known as ataxia. Involuntary, slow movements, muscles stiffness which formed abnormally is identified as spastic paralysis. An unusual crawling, bad positions of lying down, neglecting one side of the body then the other, a limited range of movement of limbs. Other signs and symptoms contain which are: less success of developmental milestones for example child's crawling, walking, speaking, hearing and eyesight problems, problems controlling in bladder and bowel movements of the CP child, seizures or convulsion, presents of drooling and problems with eating or feeding, sucking, and swallowing food and become easily disconcerted. There are four types of cerebral palsy they are: Spastic, athetoid-dyskinetic, ataxic, and hypotonic. There are three different types of spastic cerebral palsy and they are: Spastic hemiplegia is when a child with spastic hemiplegia will certainly have spasticity or have muscle stiffness on one side of the body of the child with this type of CP. This is usually occurring in just a hand and an arm or it may also involve a leg which means one side of the whole body. The side that is affected may not develop correctly and there have a chance to present speech difficulties. Though here intellect is not usually affected but seizures or

convulsion may occur. where lower limbs are affected, and the upper body has no spasticity or only a little is called spastic diplegia. The lower limb or leg and hip muscles become tight and legs become cross at the knees which make walking more difficult for those children. The crossing of the legs when upright is often stated to as scissoring position and that become tough for those children's gait or walk. Another one is Spastic quadriplegia in which all the legs, arms, and body are affected and this is the most severe form of spastic cerebral palsy and this type may involve cognitive deficits or problems, gait or walking and talking will be difficult for those affected child and seizures or convulsions may occur.

Other is athetoid or dyskinetic cerebral palsy which also known as athetoid dyskinetic cerebral palsy, this is the second most common type and in this case the child's intelligence is usually normal, but muscle problems affect the whole body and tone of muscles causes random and uncontrolled body parts movements of the child. The child will face very difficulties in gait pattern or walking, sitting, maintaining posture of the body, and speaking clearly because the tongue and vocal cords are hard to control or move. Some children have drooling problem if they have difficulties in controlling facial muscles in this type of CP.

In Ataxic cerebral palsy the most affected issues are body balance and body coordination. These children face very difficulties in fine motor skill for doing various tasks which may tying their shoelaces, when they try to buttoning up their shirts, and cutting paper or anything with scissors. The difficulties in weak or poor balance also become the reason of no gait or walk on their own feet of these children. Another is Hypotonic CP which caused from an injury or wound to the cerebellum in the brain. Muscle problems in those babies seem earlier and the baby's head and body will be floppy which look like a rag doll in these cases. There is found moderate resistance when someone tries to move the baby's limbs. In this situation the baby may take support with their elbows and knees which are loosely extended position, instead of flexed position and there may be breathing difficulties in those children which caused for lack of muscle strengths.

When a disability is happening that time the children gradually become dependent on mothers according to the severity of CP condition. Problem of children with CP become more obvious as a child grows. The permanent brain injuries are occurring such as more severe motor involvement as consequence the child severely affected and the loss of

many abilities for leading a normal life or a lower quality of life. Mothers suffer great interruption to the lives and burden of caring of the children with cerebral palsy and coping with the causes of children with CP is very difficult for the mothers. Therefore, many problems are stand up and create disruption to the family members especially mothers.

Stress is a term when people feel that they are harassed to manage with tasks related to economic factors, human relationships, environment, job related works and other situations in daily life. When a person identifies a real or imagined problems or danger to their own life and well-being then they feel stress. Sometime the word stress is used instead of feeling anxiety, feeling anxious, feel of fearful, nervousness, feeling of overwhelmed, panic attack and stressed-out in any situation by the people. According to American Psychological Association (APA) there are three types of stress those are: acute stress, episodic acute stress, and chronic stress. These three types of stress have their own features, their own characteristics, sign and symptoms, period or duration, and treatment variation.

Usually the acute stress is short-term. It has the most common and mutual sign symptoms. Acute stress which mostly caused by negative thinking and negative thoughts lead about conditions or events that have occurred recently or the situations are upcoming, the of their life events or their demands in the near future of their life. The experience of acute stress in people's lives present with everyday initiations of the stress which called to have episodic acute stress. the most harmful type of stress is chronic stress which tells if chronic stress are not treated timely it can damage severely the physical health and the mental health.

Disability affects both the children and their family members (Gardiner and Iarocci, 2012). Children with special need require more care and attention. The parents of these special children suffer from more stress in taking care of them. (Karande & Kulkarni, 2009). A study has shown that, mothers of disabled children suffers from more anxiety than fathers (Kayili,2018). According to a study (Vadivelan et.al 2020) mothers responding to the interviews had several individual-level characteristics that led them to stress. These individual-level characteristics generally are knowledge, awareness, physical abilities, beliefs, emotions and feelings etc. Mothers are the primary care provider of children with CP or any other children and also it is the mother on whom the major burden of household work is usually propelled on. Mothers who has children

with developmental disabilities or issues tend to bear more load and face more challenges than a mother with normal child. These physical load takes place during the process of caregiving which includes moving the child from one place to another, tiding up the child, feeding him/her, providing physical therapy or nurtures and playing with the child, etc. On top of that, a mother in our country has to do household chores and look after the other children and family members. The mother does not have enough time for herself and also can't take proper rest. The lack of rest directs her to several aches and pains and this hampers their ability of providing quality care for the child and this also leads to stress.

A study showed that mothers, who have children with CP can be negatively affected and may have high levels of physical burden and high levels of stress and depression with low quality of life (Ozkan,2018). A study showed that many problems were experienced by the parents while caring for the child. One of the problems experienced is the over dependence of the children on the mothers due to the inability of the children to achieve successive developmental milestones. Those mothers said that they can not sleep well for looking after their child. They could not take proper rest or give time for themselves. That restless situation caused stress and less sleep led to make them fatigue and inactive towards the whole day works. Some mothers also claimed that they sometime felt sick by doing over and over works which includes house hold chores, caring children, taking treatments, managing family, friends and others in community (Michael et al., 2019). The mother of a CP child fights with her feelings, opposite and contradictory, she feels a very strong physical and emotional aversion to the child and this makes the involvement in affection and care more terrible. (Barbosa et al.,2008).

In 2020 a study in India found that Mothers of children with disabilities felt guilty and blamed for their children, also were worried regarding the disability of their children. The feeling of guilt is very robust in mothers. They feel that it must be their own mistake which they have occurred during the pregnancy which worked behind having a child with disabilities. Those mothers also feel their motherhood to be in question because of giving birth to a child with a developmental disability. On the other hand, they had to carry the blames of community people that has been being practiced for years (Vadivelan et.al 2020).

Mothers of the children with CP worried about the future of their children. Their biggest fear was about the future of the child with a disability, thinking about the probable

problems they would face through-out their lifetime. Another study showed that 88.9% mothers of CP children feel guilt to their children (Jinming & Jianjun, 2010). According to Barbosa et. al. (2008) the birth of a disabled child had destroyed the dream of a mother of an ideal infant and, with it, the woman's expectation to be a mother is lost completely. The non-satisfaction of her wish to have an infant as she had idealized is perceived by her as a hollow area in her being and she develops a feeling of not being a mother. In 2010 a study found out in China that mothers would never give birth if they knew that the child will have a disability. The women make so many sacrifices through-out their life over the years and they end up giving up their own lives to providing care of their child (Ribeiro et al., 2016). According to Michael et. al. (2019) it was agreed by most mothers that inadequate financial resources affect the upbringing of the child. Mothers said that they have to keep borrowing money to be able to buy medicines and pay for the treatment of the child with CP. Money that would have been useful for feeding the family is used in buying medicines. The financial problem was said to be associated with the fact that only the children's fathers earn money to take care of the family. Vadivelan et. al. (2020) said the caregiving responsibility prevents mothers from career with financial gains. Even the working mother find it hard to save money for the future. Consistently financial burden is caused by having a child with developmental disabilities. Most of the times, the parents or the caregiver tolerate these financial burdens. in spite of all these issues, when a mother tries to manage savings, that also gets spent on emergencies. According to Ribeiro et. al. (2016) women having children with cerebral palsy dedicate more time to caring than mothers with normal developing children. They are linked to more psychological problems and depressive symptoms among the mothers. The problems are the not different, whether their children can walk or not and the severity of the child's conditions is not a proper predictor of maternal health. On the other hand, there is a negative impact of joblessness on the mental health of mothers. A family's financial situation can be can affected by the up bringing and caring of a child with CP. As a large financial burden on families is caused by the presence of a child with CP. (Davis et al., 2010). A study represented that the stress in the mother many is impacted by several features of the community. Urban and rural are very different with their living environments and living people because the structures. Individualistic nature of the urban area leads the society people to a very little communication and interactions among the neighbors. On the contrary, communities or society of rural areas are more open and interactions are frequent within

the living people. Based on these circumstances the stresses may vary among different community people (Vadivelan et al., 2020).

Another study said that some mother faces social biasness against the child, themselves and their family. A sense of discrimination and isolation appeared in their mind from the outlook of the community. They had a feeling of incapability of participating in community-based festivals, events and celebrations. The mothers were accused for the condition of their child. They could sense that the community people blaming and spoking behind their backs about the condition of their child (Yilmaz, 2013). One common problem reported in a study in Nigeria by all the participants was that they lacked freedom to interact with their social environment. This study observed that there is less interaction with social environment by mothers of children with CP. Participants reported that they do not have friends, as all of them ran away and others commented that they do not have time to go out with friends (Michael et al., 2019). Most of the time community people are unaware of the special needs and the reason behind children with CP. They had not ever adjusted with such children, and openly blamed parents for bringing their children in public. Due to the disability of the child the mother faces rejections from the people and with her visiting to different environment she suffers with the curiosity revealed by the looks, comments and attitudes in face of both her child and herself. When a mother with the CP child finds out that, different are not being accepted by the society and people does not offer space for them, she also adopts the same attitudes and takes the imposed standard to be normal, reinforcing her own feelings of shame of the child's differences and, thus, preferring not to expose the child publicly (Barbosa et al., 2008). According to Vadivelan et.al. (2020) there are several characteristics of the environment which causes stress in the mothers. The environment has been identified to be one of the prime factors that influence the wellbeing and health of disabled children. The elements of environment generally are the physical environment, the social environment and the attitudinal aspects of the environmental society. There are some fundamental needs of a mother who cares for a child with a developmental disability. Those are inclusive spaces where she can take the child out to interact with the society, ramps and footpaths. These needs also include disability-friendly public transport, good attitudes of the society towards children with disabilities and also workplaces that are understanding of the needs of a caregiver of children with special needs. When these are lacking of these facilities put the mother into major stress. A study in Malaysia showed that wheelchair user face difficulties to go for shopping at

shopping malls for their poor accessibility (Bashiti & Rahim 2016). Transportations are with less facilitation for the people with physical disabilities. They are less likely to have access to and are frequently not full participants within their community. These accessing problems affects the availability of the physical services, education, and social interaction which they need to lead healthy lives (Ajayi et al., 2020). CP children with severe impairment of walking ability had a much lower level of access than less impaired children on average. On every aspect of the physical environment, transport and social support that they needed at home, school and community. They usually experienced less favorable attitudes among family and friends (Dickinson et al., 2010). According to Singogo et. al. (2015) mothers experienced both social isolation and negative attitudes from the members of the community. At the same time the lack of sidewalks, ramps, functioning lifts and small indoor spaces created the physical environment's access challenging. Mothers of the children with special needs who needs to balance between works and family responsibilities, also plays caregiving role, found it extremely difficult since the timing of workplace is not flexible. Because of this, many mothers are unable to work and provide financial support to the family. An interview claimed that mother of the children with special need face difficulties to back to the work or job. They spend almost 24 hours for taking care of their children (Ridout,2019).

When children are detected with CP, their family members may go through different hardships. The circumstance usually begins with a shock. Then the feelings of guilt, sadness and helplessness reveals. The family life had to bear huge covert in psychological stipulation and up-bringing struggles for the children with disability. On the other hand, a child depending on caregiver or mother for their daily living chores, destroy normal family activities. The person being affected the most in the family is usually the mother. In such hectic situation mothers of children with cerebral palsy are more likely to suffer from stress, however, the stress factors may differ. It's the mothers who presented high levels of parental stress which has shown that the children's needs causes restriction in the social participation of the mothers and increases sufferings (Ribeiro et. al 2016).

The higher levels of stress experience of the Malaysian mother had been demonstrated by a study. There are some other factors such as increased care-giving demands, low maternal education and ethnic background which modified the running impact of

cerebral palsy on parenting stress. To change parental expectation and awareness, habilitation needs to be directed to ease the burden of daily care, minimizing hospital re-admissions and targeting proper psychosocial and emotional support at specific subgroups. Most of the time the parents of children with cerebral palsy (CP), face up-most levels of stress and little is familiar however on the non-identical sources of stress parent's experience. The relation between aspects of parental distress with CP children, in the parenting role and the child's limitations in functional skills and the child's behavioral difficulties is explored in the study (Ketelaar, 2008).

These are Mothers who has children with CP experience greater stress and emotional demands frequently. Being alone with their children in usual life increases the stress level. Not all mothers have complications of adaptation, in-spite of having highly stressful situations in life. On the other hand, the quality of life in mothers gets effected by maternal psychological situations. Standard of life is an overall perception of being well with a strong relation to the health condition of a person and ability to function. Comprehensively, the quality of life can be viewed as including all aspects of community life which have a direct and quantifiable impact on both the physical and psychological health (Bumin et al.,2008). Some studies suggested that having both child with CP and a lower socioeconomic status worked as a risk factor for mental health and caused psychological problems of the mothers of the children with CP. The studies also found that mother spending more time on child care, is in the higher the risk of mental instability among the mothers of children with cerebral palsy (Wexler, 2019).

According to Parkes et. al. (2011) mothers of children with CP experience very high level of stress, and this effect their capability of successful parenting. Also impacts the effective partnerships with their child's health care provider, and to obey instructions for their child's care. Health care provider need to know that the mothers are at highest risk of stress, those who has a child with CP and intellectual or communication impairment, or who go through pain. This stress causes their poor quality of life which lid lack of ability of caring their children.

According to Gray and Sims (2007) the best possible environment to grow up is one of the most fundamental right of every child. It is the responsibility of every society to come forward and assist with the element or supplements of that environment and provide necessary support that can help parents both physically and emotionally thus

they can assure the providence of that best possible environment. For a smooth parenting experience stress must get reduced, and that further reducing stress results in great family management.

This chapter is designed to discuss about the method of action of this study.

1. Study design

This was a cross-sectional study which had been conducted over a short period of time. Cross-sectional studies assist many determinations and the cross-sectional design is the most relevant design when there is a need of assessing the prevalence of disease, attitudes and knowledge among patients and health workers and also used in justification studies comparing, for example, different measurement instruments, and in reliability studies. According to Majid (2018) “The study design is the use of evidence-based procedures, protocols, and guidelines that provide the tools and framework for conducting a research study”. Investigator wanted to identify the level of stress of mother of children with CP and investigator also wanted to identify the common socio demographic picture, family economic status and social participation that are commonly experienced by the mothers who have children with CP at a short period of time. This type of study helped the investigator to describe an overall picture of mental status of mother who has children with CP at a specific point in time. For this reason, the cross-sectional study was more appropriate design to find out the aim and objective of this study.

2. Study site

The study was conducted at Paediatric unit, CRP Savar. It is claimed that the study setting is an important component of a research study and its nature, context of settings, environmental situations and logistics of the study setting may influence how the research study is carried out (Majid,2018). CRP is providing holistic treatment and rehabilitation to people with disabilities in Bangladesh since 1979. CRP has provided many interventions by making different units for person with disability one of them is Paediatric unit. CP is most common condition in Paediatric unit. The children with CP get treatment from the inpatient and outpatient unit such as Occupational Therapy, Physiotherapy, Speech and Language Therapy and also medical care. Here the Therapists provided Therapy through different technique such as group Therapy, functional activities, hand Therapy, modification (shoe, special chair, physical environment), physical Therapy (exercise, balance practice, walking practice etc), neuro developmental technique, articulation Therapy, swallowing management,

mothers' education about treatment techniques, dressing, feeding, communication, children condition, and also parents counseling. After discharging from the unit, a follow-up appointment data is arranged to evaluate how the child and mothers are coping after two weeks sessions from inpatient. But there is not any consideration of mothers' stress because Therapists are not aware about mothers' stress.

3. Study Population

Population for this study was the mothers who have the children with CP and who came in indoor and outdoor of paediatric unit of CRP at Savar. Population is a group of people who have a common characteristic which is of interest to the researcher (Hicks, 2000). According to Majid (2018) the study's target population that it plans to study or treat is the population of interest. In clinical or hospital-based research studies, it is sometime not appropriate or possible to recruit or include the entire population of interest. Instead, researcher will recruit a sample from the population of interest to include in their study. Krieger (2012) defined "Population as all members of any well-defined class of people, events or objects. It means therefore that any entity, group or set which constitutes a population must have at least one attribute or characteristic which is common to all of them. The population of a study therefore represents the target of the study as defined by the aims and objectives of the study. In such cases, the objective of the research study is to generalize the study findings from the sample to the population of interest".

4. Sample technique

The study participants were selected by hospital based random sampling. Here, everyone has an equal chance of being selected for the study (Suresh et al.,2011). The population of interest usually consists of too many individuals for any research project to include as participants so, sampling is an important tool for research studies. Researcher selected all sample from selected area or hospital within a certain period. Researcher collected data from all mothers of children with cerebral palsy who fill up all the inclusion and exclusion criteria and came CRP Savar for treatment 8th February 2021 to 1st March 2021. A major purpose of doing research is to infer or generalize research objectives from a sample to a larger population. The process of inference is accomplished by using statistical methods based on probability theory. A sample is a subset of the population selected, which is an unbiased representative of the larger population. Thus, the goal of sampling is to ensure that the sample group is a true

representative of the population without errors. As the researcher conducted the study for academic purpose and has time limitation to complete data collection so, this method was appropriate for the researcher to collect more data within limited time and researcher took all mothers of children with CP as a sample who came to the centre or hospital in February 2021. So, this group become a random one in whole population or the mothers of children with CP who came for treatment in other months.

4.1 Sample Size

As per Crochran's sample size determination formula, the sample size of the study will be-

$$n = \frac{z^2 pq}{d^2} \text{ where, } n = \text{estimated sample size}$$

z = constant number based on the confidence interval

In 95% CI, $z = 1.96$

p = prevalence rate of Cerebral Palsy in Bangladesh is 3.4, so the p value would be 0.034

$q = 1 - p$

d = error margin (5% = 0.05)

So, as per the formula the sample size would be 344.

According to Oribhabor, (2019) when selecting a sample size for a research, we need some minimal prior knowledge about the target population; with this and some reasonable expectations from those target population and we can estimate a sample size required to achieve a reasonable estimate of population characteristics.

Researcher selected 111 participants for this study. Because of the COVID19 pandemic situation researcher had limited time for data collection. Due to lock down situation sample of target population was not available. Larger sample is more likely to be representative of the population than a smaller one. The appropriate size for the sample is not easy to determine, since it depends very much on the subject being studied, as well as on the researcher knowledge (Hicks, 2000). Basically, for this reason researcher conducted the study with 100 participants.

4.2 Inclusion Criteria

- Mother who is a primary caregiver of the children with CP.
- At least take two weeks intervention or therapy sessions or programs.

4.3 Exclusion Criteria

- Younger children (age below 1 year).
- Other care givers.

5. Data collection tools and instruments

Researcher used consent form, socio-demographic questionnaire, standardize scale, a close ended question about social participation. Pencil and pen for collecting data from the participants.

□ Consent Form

Before data collection, the researcher took consent from all participants giving written consent form (Appendix-3) and assured that all the participants' information would be kept confidential and their name and address would not be published in the study.

□ Socio-demographic Questionnaire

Researcher used self-developed Socio-demographic questionnaire (including age, occupation, educational status marital status, care giving duration, religion, number of children, financial status) to identify the demographic characteristic of the mother of children with CP (Appendix-4).

□ Standardize Scale Named Parental Stress Scale

Researcher used Parental stress Scale to identify the level of stress of mother who have children with CP (Appendix -5). This 18 scale is developed by Berry and Jones (1995) which provides a measure that have positive and negative aspects of parenting. Specially, stressful aspects focused on in this scale. The Parental Stress Scale (PSS) is a self-report scale that contains 18 items representing pleasure or positive themes or subjects of parenthood which consist emotional benefits, self-enrichment, personal development and negative components which are demands on resources, opportunity costs and restrictions. Parents are asked to agree or disagree with 18 items and each item on a five-point scale which define by: strongly disagree (1), disagree (2), undecided (3), agree (4), and strongly agree (5). The eight positive items has reverse scored such as items 1, 2, 5, 6, 7, 8, 17, and 18 should be reverse scored as these: (1=5) (2=4) (3=3) (4=2) (5=1). The item scores are then summed and overall possible scores on the scale range from 18 – 90. In PSS the higher scores on the scale indicate the higher stress level.

The PSS is a much-used instrument in both research and clinical practice. According to Louie, Cromer, and Berry who involving the PSS across 25 studies within two eras of research. Its wide application within research includes various people in studies and they also include first-time parents, parents of children with physical disability and

autism spectrum disorder which was population-based samples, a mix of clinical and non-clinical samples (Narde & Hukkelberg,2020).

□ **Questions about social integration**

Researcher used self-developed close ended questions about social integration to find out the situation of social participation of the mothers of children with CP. (Appendix-6)

6. Data collection:

At first, researcher took permission from the in-charge of pediatrics unit of CRP at Savar for collecting data (Appendix-2). Before collecting data, time and place were confirmed with participants and the study aim and purpose were explained to all participants. All the participants were given consent form for taking permission from them to participate in this study and they were given opportunity to ask any types of study related questions. The participants who could not read the consent form, researcher read the consent form in front of the participants. After getting written consent, researcher started to collect data. At first, the researcher collected general information using self-developed socio-demographic questionnaire and also collect information about social participation by self- developed questions about social integration then conducted face to face interview by using structured questionnaire named Parental Stress Scale to assess the mothers stress level. By using this method researcher became able to interact directly and to understand the participant's nonverbal language easily. According to participants understanding level, sometimes the question was described in native language so that the participants understood perfectly and answered correctly. After successfully collecting data, researcher leaves the participants by giving thanks to all participants to be a part of study willingly.

7. Field test

Prior the final study investigator conducted a field test with 5 participants. Investigator collected data from these participants used all mentioned data collection instruments and following whole data collection procedure. This field test was done for checking participants understood the questions or not and how participants responded to questionnaire. The investigator collected information from those 5 participants successfully via this questionnaire. It helped to prove the validity of the questionnaire in this study. Hays & Brown, (2005) claimed that the field testing involves running an

early version of a survey or study to a less sample of the target people and by testing the surveyor study in an actual environment the survey designers or investigators can gather valuable information that helps them improve survey objects and materials.

8. Data analysis:

Data analyzed by using simple descriptive statistics using the software package of excel and SPSS (Statistical Package for the Social Sciences) Version 24. Different statistical also used for different comparison between the independent and dependent variables. According to Trochim (2020) descriptive statistics are used to describe the basic features of the data in a study. They provide simple summaries about the sample and the measures. Together with simple graphics analysis, they form the basis of virtually every quantitative analysis of data. Descriptive statistics summarize and organize characteristics of a data set. A data set is a collection of observations from a sample or whole population. In quantitative study, after collecting data, the first step of statistical analysis is to describe characteristics of the responses, such as the average of one variable (e.g., age), or the relation between two variables (e.g., age and weight). The next phase is inferential statistics, which help to decide whether the data confirms or disproves the hypothesis and whether it is generalizable to a larger population (Bhandari, 2020). Descriptive statistics help us to simplify large amounts of data in a practical way. Each descriptive statistic reduces lots of data into a simpler summary. In this study the Chy square test was done to see if there any relations between the sociodemographic condition and the level of stress of the mothers of the children with cerebral palsy. According to Hayes (2020) A chi-square (χ^2) statistic is a measure of the difference or associations between the observed and expected frequencies of the outcomes of a set of events or variables.

9. Ethical consideration:

The investigator maintained some ethical consideration in this research. After getting the permission of doing this study from the Institutional Review Board (IRB) (appendix-1) the investigator started to do it and also maintain the BMRC and WHO code of conduct for responsible Research. Researcher obtained permission for conducting data collection from the In-charge of pediatrics unit of CRP at Savar (Appendix-2). The investigator informed the participants before to invite participation in the study and ensure that all participants informed about their rights and reserves and

about the aim and objectives of the study. Before starting the interview, the investigator used a written consent (appendix-3) to take the permission of each participants of the study. It was also ensured that all kinds of confidentiality were highly maintained. The investigator ensured not to leak out any type of confidentialities and the participant had the rights to leave the study when she wants. All participants had given equal rights to ask any types of study related questions. Investigator was accountable to the participants to answer any types of study related questions. Aim and objectives of the study were informed to all participants. Investigator did not create any mental pressure to participants to engage in this study and gave the priority of participant's willingness. Researcher also informed the participants that they did not get direct benefit from this study. The investigator also ensured that the organization was not hamper by this study.

1. Socio-demographic Characteristics of the participants

Table-1 Shows the socio-demographic picture including age, educational status, marital status, occupation, living area, care giving duration, number of children and Socio-economic status of all participants. The study was conducted on 111 participants where all of them were mother of children with CP.

Among them most of the participants 51.1% (n=57) were in between the age of 24-28 years and 20.0% (n=23) were 19-23 years, 22.5% (n=25) were 29-33 years, 5.4% (n=6) were 34-38 years. The mean age of the participants was 26.35 years and standard deviation was 3.92 (26.58±3.82).

Findings on education level shows that most of the participants 36.9% (n=41) had education up to the level of secondary school, 28.8% (n=32) had education up to intermediate level, 20.7 % (n=23) had education up to primary level, 10.8% (n=12) had education up to Bachelors level. The illiterate participants were recorded to be 1.8% (n=2) and 0.9% (n=1) had education up to Masters and above. In this study, majority of the participants 96.4% (n=104) were married and 3.6% (n=4) were divorced. In this study, it was found that most of the participants 82.9% (n=92) were housewife, 12.6% (n=14) were service holder and 4.5% (n=5) were student. Among the participants 38.7 % (n=43) came from semi-urban areas, 36.0 % (n=40) from rural and 25.2% (n=28) from urban areas. In this study, it was found that maximum number of participants 75.7% (n=84) took care of their children for 11 hours and above. 21.6 % (n=24) participants took care their children for 6-10 hours, 2.7% (n=3) for 1-5 hours. Among all participants 45.9% (n=51) participants had 2 children, 41.4% (n=46) had 1 only child and 12.6% (n=14) had 3 children. In this study, 46.8% (n=52) participants came from lower middle socio-economic status, 26.1% (n=29) came from higher middle socio-economic status and 26.1% (n=29) came from Low socio-economic status and rest of the 0.9% (n=1) came from the high socio-economic status.

Table-1: Common Socio-demographic profiles of all participants

Variables	Frequency	Percentage (%)
Age (in year)		
19-23	23	20.7
24-28	57	51.1
29-33	25	22.5
34-38	6	5.4
Mean Age \pm SD		
26.58 \pm 3.82		
Educational Status		
Illiterate	2	1.8
Primary	23	20.7
Secondary	41	36.9
HSC	32	28.8
Bachelor	12	10.8
Masters and Above	1	0.9
Marital Status		
Married	107	96.4
Divorced	4	3.6
Occupation		
Student	5	4.5
Housewife	92	82.9
Service Holder	14	12.6
Living Area		
Rural	40	36.0
Semi Urban	43	38.7
Urban	28	25.2
Care Giving Duration		
1-5 Hours	03	2.7
6-10 Hours	24	21.6
11 Hours and above	84	75.7
Number of Children		
1	46	41.4
2	51	45.9
3	14	12.6
Socio Economic Status		
Low SES	29	26.1
Lower Middle SES	52	46.8
Higher Middle SES	29	26.1
High SES	01	0.9
Total participants, N=111		

2. Common picture of Stress level among all participants according to Parental Stress Scale-PSS.

Table-2: Stress level among all participants according to Parental Stress Scale-PSS.

Parental stress symptoms	Strongly disagree %	Disagree %	Undecided %	Agree %	Strongly agree %
I am happy in my role as a parent.	14.4	44.1	15.3	19.8	6.8
There is little or nothing I wouldn't do for my child (ren) if it was necessary	0.0%	0.0%	0.0%	66.7%	33.3%
Caring for my child (ren) sometimes takes more time and energy than I have to give.	0.0	2.7	0.0	51.4	45.9
I sometimes worry whether I am doing enough for my child(ren).	24.3%	43.2%	28.8%	2.7%	9.0%
I feel close to my child(ren).	0.0%	0.0%	22.5%	45.0%	32.4%
I enjoy spending time with my child(ren).	0.0%	1.8%	15.3%	55.9%	27.0%
My child(ren) is an important source of affection for me.	0.0%	0.0%	5.4%	52.3%	42.3%
Having child(ren) gives me a more certain and optimistic view for the future.	10.8%	16.2%	12.5%	34.3%	26.1%
The major source of stress in my life is my child(ren).	35.1	49.5	8.1	6.3	9.0
Having child(ren) leaves little time and flexibility in my life.	2.7	9.9	13.5	45.9	27.9
Having child(ren) has been a financial burden.	0.0	27.9	6.3	32.4	33.3
It is difficult to balance different responsibilities because of my child(ren).	1.9	9.0	7.2	47.7	34.2

The behavior of my child(ren) is often embarrassing or stressful to me.	0.9	22.5	20.7	33.3	22.5
If I had it to do over again, I might decide not to have child(ren).	6.3	18.9	13.5	39.6	21.6
I feel overwhelmed by the responsibility of being a parent.	3.6	27.0	37.8	26.1	5.4
Having child (ren) has meant having too few choices and too little control over my life.	1.8	9.0	13.5	58.6	17.1
I am satisfied as a parent.	12.6	34.2	24.3	21.6	7.2
I find my child(ren) enjoyable.	0.0%	2.7	8.1	73.9	15.3

3. The most common causes of stress among all participants

This table-3 represents that the most common causes of stress among all participants which were agreed and strongly agreed by most of the participants. In the present study result found that 97.3 % (n=108) of all participants reported that they lost their more time and energy due to caring their children. In this study, losing more time and energy was the very most common cause of stress among mothers of children with cerebral palsy according to their opinions. The second most common cause of stress was difficulties to maintain other responsibilities due to spending more time for caring their children and 81.9% (n=91) of all participants reported poor balance in their work. 75.7%(n=84) participants reported that they felt lack of choice and control in their life and this was the third most common cause of stress among participants. Among 111 participants 65.7% (n=73) participants reported having children had been financial burden for them,73.8% (n=82) participants reported lack of flexibility in life, 60.4% (n=66) participants reported they were worrying about their own and children's future, 55.8% (n=62) Participants reported they felt embarrassing situation because of their children's behavior.

Table 3: The most common causes of stress among all participants

Most common causes of stress	Agree	Disagree
Lost more time and energy	97.3 %	2.7%
Difficulties to maintain other responsibilities	81.9%	18.9%
Lack of choice and control in life	75.7%	24.3%
Financial burden	65.7%	34.3%
Lack of flexibility in life	73.8%	26.2%
Worrying about future	60.4%	39.6%
Felt embarrassment	55.8%	44.2%

4. Level of Stress among participants

This bar chart (figure-2) represents that in this study, 8.1% (n=9) of all participants had low level of stress as their obtained score was 36 to 45 according to the PSS which have 18 to 90 score, 76.5% (n=85) participants high level of stress and they scored 45 to 60 , 14.4% (n=17) participants had very high or extreme level of stress according to PSS and their score was 60 to 72.

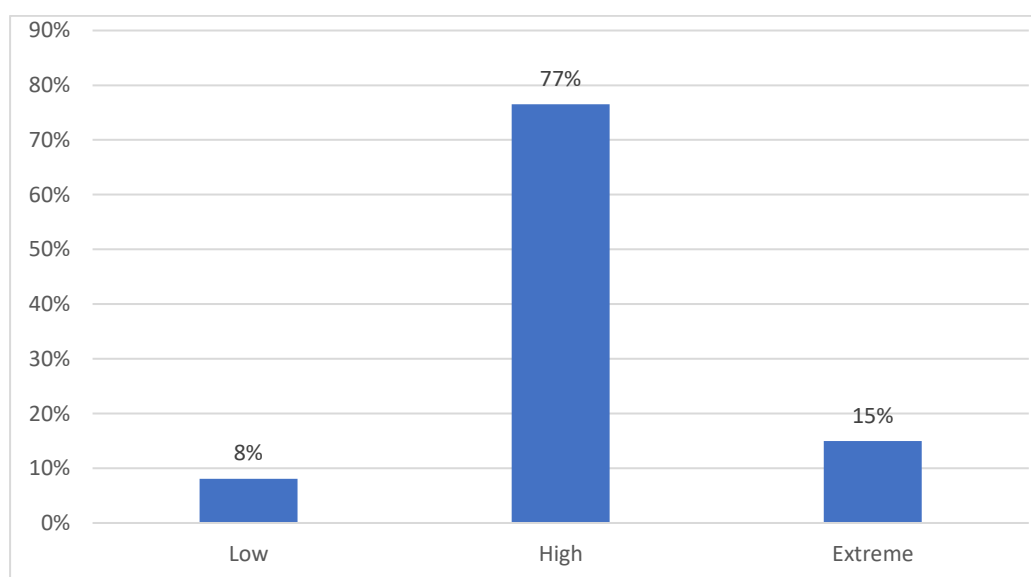


Figure 2: The level of Stress among participant

5. Association between socio-demographic characteristics and level of Stress of the participants:

5.1 Association between educational status and level of stress of the participants.

Table-4 shows that the Chi-square value is 0.943 which is greater than 0.05. If chi-square value is more than 0.05 then there is not significant association among the variables.

So, there is no significant association between the educational status of the mothers of children with cerebral palsy and their stress level.

Table-4: Association between educational status and level of stress.

Educational status	Level of stress			P value	Chi-Square (χ^2) value
	Low Stress	High Stress	Very High Stress		
Illiterate	0	2	0	0.943	4.091
Primary	1	19	3		
Secondary	1	38	2		
HSC	2	28	2		
Bachelor	1	11	0		
Masters and Above	0	1	0		

Total participants (N=111)

5.2 Association between Occupation and level of stress of the participants.

Table-5 represents that the Chi-square value is 0.318 which is greater than 0.05. So, there is no significant association between the occupation of the mothers of children with cerebral palsy and their stress level.

Table-5: Association between occupation and level of stress.

Occupation	Level of stress			P value	Chi-Square (χ^2) value
	Low Stress	High Stress	Very High Stress		
Student	1	4	0	0.318	4.712
Housewife	3	82	7		
Service Holder	1	13	0		

Total participants (N=111)

5.3 Association between living area and level of stress of the participants.

In Table-6, here the chi-square score is 0.013 which is less than 0.05. So, we can say that the stress level of the mother of children with cerebral palsy differs as per their living area. There is significant association between the living area and the stress level of mother of children with cerebral palsy.

Table-6: Association between living area and level of stress.

Living Ares	Level of stress			P value	Chi-Square (χ^2) value
	Low Stress	High Stress	Very High Stress		
Rural	2	32	6	0.013	12.722
Semi Urban	0	42	1		
Urban	3	25	0		

Total participants (N=111)

5.4 Association between care giving duration and level of stress of the participants.

From Table-7 it was found that the Chi-square value is 0.494 which is greater than 0.05. So, there is no significant association between the care giving duration of the mothers of children with cerebral palsy and their stress level.

Table-7: Association between care giving duration and level of stress.

Caregiving Duration in hours	Level of stress			P Value	Chi-Square (χ^2) value
	Low Stress	High Stress	Very High Stress		
1-5 Hours	0	3	0	0.494	3.396
6-10 Hours	2	22	0		
11 Hours and above	3	74	7		

Total participants (N=111)

5.5 Association between number of children and level of stress of the participants.

From Table-8 it showed that the Chi-square value is 0.499 which is greater than 0.05. So, there is no significant association between the number of children and the stress level of the mothers of children with cerebral palsy.

Table-8: Association between number of children and level of stress.

Number of Children	Level of stress			P value	Chi-Square (χ^2) value
	Low Stress	High Stress	Very High Stress		
1	4	39	3	0.499	3.362
2	1	47	3		
3	0	13	1		

Total participants (N=111)

5.6 Association between Socio Economic status and level of stress of the participants.

Here is Chi-square value is 0.026 which is smaller than 0.05. So, there is significant association between the Socio-Economic Status of the mother of children with cerebral palsy and their stress level. ($P < 0.05$). From the table-9 we can see that out of total 29 participants of Low SEC, 96.9% participants are suffering from high level of Stress. Where 94% of the Lower Middle SES participants suffer High level of stress. 93% of the participants of Higher Middle SES suffers High level of Stress.

Table-9: Association between Socio Economic status and level of stress.

Socio Economic Status	Level of stress			P value	Chi-Square (χ^2) value
	Low Stress	High Stress	Very High Stress		
Low SES	1	22	6	0.026	14.314
Lower Middle SES	2	49	1		
Higher Middle SES	2	27	0		
High SES	0	1	0		

Total participants (N=111)

6. The situation of Social Integration of the participants:

6.1 Social Participation

Difficulties in social Participation	Agreed	Disagreed
Participate in social functions with child	42.3%	57.7%
Lack of interest to participate at any social functions because of the physical burden to carry child	60.4%	39.6%
Lack of interest to participate at any social events because of the negative attitude of the community people	58.6%	41.4%
Frequently can go outside for shopping or any other necessary activities with child	37.8%	62.2%

Table- 10: Social participation of all participants

This table-10 showing that 57.7% mother had difficulties to participate in social functions and most of them (60.4%) claimed that they had low interest to attend in different social function or ceremony because of they have to carry their children as a child with cerebral palsy was not functional independent. In this present study 58.6% participants also said they feel poor interest to join any social function due to the negative attitude of the society people and 62.2% participants said they can't go outside frequently for shopping and other necessary activities along with their child. This result showing that mother of children with Cerebral palsy had limitation of social participation due to physical burden, negative attitude of society people. Lack of social participation restrict their sharing feelings with others and also restrict their leisure and joy which become the cause of stress among all mothers.

6.2 Accessibility in living and social environment

Available of accessibility	Agreed	Disagreed
Have accessibility in market or shopping malls with child	36.9%	63.1%
Difficulties to go outside with child for attending any social function, shopping or any other necessary activities because of poor accessibility in living environment	74.8%	25.2%
Find lack of options of public transport with child	79.3%	20.7%
Have accessibility in Public transports with child	20.7%	79.3%

Table -11: Accessibility in living and social environment of participants

Table-11 represent that 63.1% mothers said they didn't find accessibility in market place and shopping malls with their children with CP and 74.8% mother reported that they had difficulties to go outside with child for attending any social function, shopping or any other necessary activities because of poor accessibility in living environment. In this study 79.3% of the participant claimed that they found lack of options of public transport with child, 79.3% reported that no accessibility in public transport. This poor accessibility causes their low participation in social activities, works, services which led them towards the stress.

6.3 Social relationship

Difficulties in maintaining social relationship	Agreed	Disagreed
People of the community or society supportive	36.9%	61.1%
Having problems maintaining relationships with friends and relatives	64.9%	35.1%
Feel isolated from others in the society	72.1%	27.9%

Table-12: Social relationships picture of the participants

This table- 12 reporting that 61.1% participants said their community people are not supportive to them and their children with CP. 64.9% mothers claimed that they had problem in maintaining communication and good relationships with friends and relatives. This because of spending more time for caring their children, negative attitude of the society people, poor accessibility in living area, lack of accessibility in public transport and 72.1% participants said they feel isolated themselves from the society and social activities.

In this study, all participants were the mother of children with CP and the study result represented that the mother of children with CP had higher stress level. The first responsible person to take care of a child is the mother (Saywer *et al.* 2011). Many researchers have suggested that mothers bear a greater care giving burden than father. Mothers spend huge period of time in look after their children with special needs and other members in the family and they also tend to experience greater depression, stress, poorer well-being, and worse physical health outcomes than fathers in care giving roles (Zanon and Batista, 2012). A study showed that mothers can be destructively affected and may have higher levels of physical load and higher stress level with low quality of life with children with cerebral palsy (Ozkan, 2018).

The study was conducted on 100 participants where all of them were mother of children with CP. Among them most of the participants 51.0% (n=57) were in between the age of 24-28 The mean age of the participants was 26.58 years and standard deviation was 3.92 (26.58±3.8). A study showed that stress, anxiety and depression level were increased much more which observed in younger mothers (Kayili,2018). The current study findings on education level shows that most of the participants 28.8% (n=32) had education up to the level of secondary school. In this study, it was found that most of the participants 82.9% (n=92) were housewife. Among the participants 38.7% (n=43) came from semi-urban areas, 36.0 % (n=40) from rural and 25.2% (n=28) from urban areas. This current study found that there is an association between living area and the mothers stress level. Most of the participant came from rural and semi urban area and majority had high level of stress.

A study represented that the stress in the mother many is impacted by several features of the community. Urban and rural are very different with their living environments and living people because the structures. Individualistic nature of the urban area leads the society people to a very little communication and interactions among the neighbors. On the contrary, communities or society of rural areas are more open and interactions are frequent within the living people. Based on these circumstances the stresses may vary among different community people (Vadivelan *et.al.*, 2020).

The community people in rural or semi urban area can communicate with the mothers of the children with CP more than urban neighbors and as they have lack of option to know about the special need children, they blame the mothers and show negative

attitude which increased the stress of the mothers. A study claimed that When a mother with the CP child finds out that, different are not accepted by the society and people does not offer space for them, she also adopts the same attitudes and takes the imposed standard to be normal, she reinforcing her own feelings of shame of the child's differences and, thus, preferring not to expose the child publicly (Barbosa, 2008).

Usually in rural living area the availability of health services, information and education about disability are less than urban area which also may cause for variation of stress. A study in Spain found that the mothers and their children with disabilities who live in rural context, influenced the construction of disability. This rural context does not allow a well-paid job for mother and there is lack of resources, environmental social supports which have a huge effect of wellbeing of the mothers of the children with special needs (Garlito et al., 2020).

In this study, it was found that maximum number of participants 75.7% (n=84) took care of their children for 11 hours and above and also found that the most of the mother was housewife and they had to look after their children for 11 hours and more. In Bangladeshi context most of the mothers perform domestic activities as their productive role. So, they stay in home most of the time. As a result, they are more engaged to take care of their children with CP. According to a study Vadivelan et.al. (2020) Mothers are the primary care provider of children with CP or any other children and also it is the mother on whom the major burden of household work is usually propelled on. Mothers who has children with developmental disabilities or issues tend to bear more load and face more challenges than a mother with normal child. These physical load takes place during the process of caregiving which includes moving the child from one place to another, tiding up the child, feeding him/her, providing physical therapy or nurtures and playing with the child, etc. Moreover, to all of this the mother also has the work of the household activities and look after other children and other members in the family. The mother does not get enough or proper time for rest and this lack of rest directed to muscle spasm and pains in the body which hampered their ability to provide quality or proper care for the special need child and this also cause of stress of those mother. Mothers felt guilty because of having disabled child, fatigue due to the many hours of caring for the child, lack of rest (Zawada et al., 2011).

But this current study found there is an association between the socio-economic status and the stress level of the mothers of CP child. A study conducted by Sajedi et. al. (2010) showed that there was no relation between the job of mother's, the academic

status of mother's , their birth information, the number of their children, their home size and the number of family members of those participants, severity of disability with the mothers' stress and depression because the tolerance of high level of stress found in mothers of children with different levels of disability. A study showed that the parenting stress level are experienced by the parents of cerebral palsy children was found to be associated with job status or income status (Ramanandi & Rao, 2015). According to Kayili (2018) stress levels of parents with disabled children differ according to their level of income.

In this study it was found that 91% mothers had high level of stress. The most common causes of their stress were losing more time and energy due to taking care of their children, lack of flexibility in their own life. Children with special needs have need of more care, and their parents feel more stress during look after of them (Karande & Kulkarni, 2009). According to Parkes et. al. (2011) mothers of children with CP experience very high level of stress, and this effect their capability of successful parenting. Also impacts the effective partnerships with their child's health care provider, and to obey instructions for their child's care. Health care provider need to know that the mothers are at highest risk of stress, those who has a child with CP and intellectual or communication impairment, or who go through pain. This stress causes their poor quality of life which lead lack of ability of caring their children.

According to Zanon and Batista (2012) the need of constant assistance for children with CP can make their mothers become stressed. Mother's wellbeing depends on the child's level of impairment, care giving demand, and family structure. Mother of children with CP require more attention and longer duration of care, these excessive responsibilities can negatively affect their physical, psychological and social health (Kumari & Joseph, 2014, Marron, 2013 and Al Gamal, 2013).

Another major cause of stress which was claimed by 65.7%% mothers of children with CP was financial burden. They face difficulties to manage all expenses of their children including their service charge, medicines, equipment, aids etc. A study in Bangladesh reported that financial needs were the highest priority in the family with CP child (Nuri et al., 2018). According to Michael et. al. (2019) it was agreed by most mothers that inadequate financial resources affect the upbringing of the child. Mothers said that they have to keep borrowing money to be able to buy medicines and pay for the treatment of the child with CP. Money that would have been useful for feeding the family is used

in buying medicines. The financial problem was said to be associated with the fact that only the children's fathers earn money to take care of the family. Vadivelan et.al. (2020) said the caregiving responsibility prevents mothers from career with financial gains. Even the working mother find it hard to save money for the future. Consistently financial burden is caused by having a child with developmental disabilities. Most of the times, the parents or the caregiver tolerate these financial burdens. in spite of all these issues, when a mother tries to manage savings, that also gets spent on emergencies. According to Ribeiro et. al. (2016) that an undesirable impact on the mental health of mothers of children with special needs is joblessness. Another study reported that looking after the children and up bringing of a child with CP can affect a family's economic situation and the presence of a child with CP can result in a huge financial burden on the families. (Davis et al., 2010).

In this present study the second highest (81.9%) cause of stress of the mothers was they faced difficulties to make a balance with other responsibilities due to spending more time for taking care of their children. Due to the mother's central role in family life and responsibilities for childcare, she will experience a higher level of stress and anxiety (Borzoo et al., 2014). Another study presented that the mother of the children with special need spend almost 24 hours for taking care of their children (Ridout,2019). That cause they face difficulties in role balance with other responsibilities. A study showed that many problems were experienced by the parents while caring for the child. One of the problems experienced is the over dependence of the children on the mothers due to the inability of the children to achieve successive developmental milestones. Those mothers said that they cannot sleep well for looking after their child. They could not take proper rest or give time for themselves. That restless situation caused stress and less sleep led to make them fatigue and inactive towards the whole day works. Some mothers also claimed that they sometime felt sick by doing over and over works which includes house hold chores, caring children, taking treatments, managing family, friends and others in community (Michael et. al., 2019).

Another most claimed cause of stress among mothers (75.7%) in this present study was they had lack of choice and control in their life. A study found that mother spending more time on child care, is in the higher the risk of mental instability among the mothers of children with cerebral palsy (Wexler, 2019). Another study showed that, It's the mother who presented high levels of parental stress which has shown that the children's need causes restriction in the social participation of the mothers and increases sufferings

(Ribeiro et. al., 2014). The spending of more time and energy for caring the special need children, lack of rest, no leisure time, restriction of social participation cause lack of choice and control in the mother's own life which make result of stressful life.

In this present study 55.8% mother reported that they felt embarrass because of their child. This was also a common cause of stress among participants. A study showed that the mother of a CP child fights with her feelings, opposite and contradictory, she feels a very strong physical and emotional aversion to the child and this makes the involvement in affection and care more terrible. (Barbosa, 2008).

In 2020 a study in India found that Mothers of children with disabilities felt guilty and blamed for their children, also were worried regarding the disability of their children. The feeling of guilt is very robust in mothers. They also had to bear the blame that the community made for them. They felt embarrassing situation in front of the society with their child's condition and behavior (Vadivelan et al.,2020). Another study showed that 88.9% mothers of CP children feel guilt to their children and mothers would never give birth if they knew that the child will have a disability (Jinming & Jianjun, 2010). This study found that 60.4% mother had been worrying about the future of their children which increased their stress level. Their biggest fear was about the future of the child with a disability, thinking about the probable problems they would face through-out their lifetime (Jinming & Jianjun, 2010). Another study showed that the parents were worried that the child may not be able to perform the normal roles of apparently healthy children and they fear the child may be dependent all through life which may led not to be able to acquire education like any regular child. Even when one of the mothers is influenced of gain in developmental milestone of the child, she submits that these milestones may come late. What the future holds for the children with CP has always been with mix feeling among their mothers (Michael, et al., 2019).

In this study 57.7% mother claimed that they cannot attend or participate in social function with their children. This restriction of attending any social activities limited their sharing of feelings and emotions with others and also restricted their leisure time and enjoyment which cause stress. Among 111 participants 60.4% mothers said that they felt lack of interest to attend any social function because of the physical burden to carry their children. In a study reported that musculoskeletal pain (62.5%) and Low Back Pain (42%) rates were high in mothers having cerebral palsy child (Kaya et al., 2010). Mental health problem has a significant adverse effect on the physical health

and social relationships of individuals (Saywer et al., 2011). Psychological distress, depressed mood was associated with transition to chronic LBP (Kaya *et al.*, 2010). Another study showed that mothers, who have children with CP can be negatively affected and may have high levels of physical burden and high levels of stress, lack of interest in social activities and lead low quality of life (Ozkan,2018).

This present study also found 58.6% mother expressed that the negative attitude of the society people made them low interest to join any social ceremony. A study said that some mother faces social biasness against the child, themselves and their family. A sense of discrimination and isolation appeared in their mind from the outlook of the community. They had a feeling of incapability of participating in community-based festivals, events and celebrations. The mothers were accused for the condition of their child. They could sense that the community people blaming and spoking behind their backs about the condition of their child (Yilmaz, 2013). One common problem reported in a study in Nigeria by all the participants was that they lacked freedom to interact with their social environment. This study observed that there is less interaction with social environment by mothers of children with CP. Participants reported that they do not have friends, as all of them ran away and others commented that they do not have time to go out with friends (Michael et al., 2019). Most of the time community people are unaware of the special needs and the reason behind children with CP. They had not ever adjusted with such children, and openly blamed parents for bringing their children in public. Due to the disability of the child the mother faces rejections from the people and with her visiting to different environment she suffers with the curiosity revealed by the looks, comments and attitudes in face of both her child and herself. When a mother with the CP child finds out that, different are not being accepted by the society and people does not offer space for them, she also adopts the same attitudes and takes the imposed standard to be normal, reinforcing her own feelings of shame of the child's differences and, thus, preferring not to expose the child publicly (Barbosa, 2008).

More than half participants (62.2%) in this study said they cannot go outside frequently for shopping or other necessary activities with their children and this caused for lack of accessibility in their living area, society, market place, public transport etc. In this study 63.1% mother said they don't have any accessibility in market place or shopping mall and 74.8% said they felt difficulties to go outside or shopping mall, attending social function due to poor accessibility in their living area. This decrease their participations in social activities and increase their stress level. According to Vadivelan et.al. (2020)

there are several characteristics of the environment which causes stress in the mothers. The environment has been identified to be one of the prime factors that influence the wellbeing and health of disabled children. The element of environment are generally the physical environment, the social environment and the attitudinal aspects of the environmental society. There are some fundamental needs of a mother who cares for a child with a developmental disability. Those are inclusive spaces where she can take the child out to interact with the society, ramps and footpaths. These needs also include disability-friendly public transport, good attitudes of the society towards children with disabilities and also workplaces that are understanding of the needs of a caregiver of children with special needs. When these are lacking of these facilities put the mother into major stress. A study in Malaysia showed that wheelchair user face difficulties to go for shopping at shopping malls for their poor accessibility (Bashiti & Rahim, 2016). Transportations are with less facilitation for the people with physical disabilities. They are less likely to have access to and are frequently not full participants within their community. These accessing problems affects the availability of the physical services, education, and social interaction which they need to lead healthy lives (Ajayi et al., 2020). CP children with severe impairment of walking ability had a much lower level of access than less impaired children on average. On every aspect of the physical environment, transport and social support that they needed at home, school and community. They usually experienced less favorable attitudes among family and friends (Dickinson et al., 2010). According to Singogo et.al. (2015) mothers experienced both social isolation and negative attitudes from the members of the community. At the same time the lack of sidewalks, ramps, functioning lifts and small indoor spaces created the physical environment's access challenging

From this study it was found that 79.3% mother reported they had lack of option in public transport with their children and they found there was no accessibility in public transport. This lack of option of their transportation limit their participation, communication and decreased their reach to proper services for their children. That made them insecure for their children's future which create a high level of stress among the mother of children with cerebral palsy.

According to Vadivelan et.al. (2020), several characteristics of the environment causes stress of the mothers. The elements of environment generally are the physical environment, the social environment and the attitudinal aspects of the existing society.

There are some fundamental needs of a mother who cares for a child with a developmental disability. Those are inclusive spaces where she can take the child out to interact with the society, ramps and footpaths. These needs also include disability-friendly public transport, good attitudes of the society towards children with disabilities. Another study showed that Transportations are with less facilitation for the people with physical disabilities. They are less likely to have access to and are frequently not full participants within their community. These accessing problems affects the availability of the physical services, education, and social interaction which they need to lead healthy lives (Ajayi et al. 2020). CP children with severe impairment of walking ability had a much lower level of access than less impaired children on average. On every aspect of the physical environment, transport and social support that they needed at home, school and community. They usually experienced less favorable attitudes among family and friends (Dickinson, et.al 2010).

In this present study 61.1% mother said their society people were not supportive to them and their children. A study showed that some mother faces social biasness against the child, themselves and their family. The mothers were accused for the condition of their child. They could sense that the community people blaming and spoking behind their backs about the condition of their child (Yilmaz, 2013). Another study reported that most of the time community people are unaware of the special needs and the reason behind children with CP. They had not ever adjusted with such children, and openly blamed parents for bringing their children in public. Due to the disability of the child the mother faces rejections from the people and with her visiting to different environment she suffers with the curiosity revealed by the looks, comments and attitudes in face of both her child and herself. (Barbosa, 2008). In a study participant reported that they do not have friends, as all of them ran away and not helpful towards them at all (Michael et. al., 2019). In this study 64.9% mother said they had problem in maintaining relationship with their friends and relatives and 72.1% said they felt isolated from their friends, relative and society people. A study said that some mother had a feeling of incapability of participating in community-based festivals, events and celebrations. (Yilmaz, 2013). One common problem reported in a study that all the participants had lack of freedom to interact with their social environment. This study observed that mothers of children with CP has less interaction with social environment. Participants reported that they do not have friends, as they do not have time to go out

with friends (Michael et. al., 2019). According to Singogo et.al. (2015) mothers experienced both social isolation and negative attitudes from the members of the community. At the same time the lack of sidewalks, ramps, functioning lifts and small indoor spaces created the physical environment's access challenging. Another study said that some mother faces social biasness against the child, themselves and their family. A sense of discrimination and isolation appeared in their mind from the outlook of the community. (Yilmaz, 2013). This isolation makes them fall into stress which effect on their daily life specially the quality care of their children with cerebral palsy. A study said that educational consultations about the care of a disabled child should also organized for other family members and other family members will also be involved in the care-giving of the children with disability and will share and reduce the burden that falls mainly on mother and taking both physical and social measures for mother to spend more time in social settings with their children with disabilities will help reduce their levels of depression, anxiety and stress (Kayili,2018). The organizations, health care providers, family members and the community people all should be supportive to the mothers of the children with CP to ease their stress. To gain a better outcome from the intervention of the children with CP the mother should stress free and motivated to the intervention and instruction for their children. So, this study found that mothers are suffering high level of stress. Health care provider of the children with CP and the organization who providing health services should focus on this factor and need to take necessary steps. Govt. should also consider this situation by observing the availability of services, financial considerations, accessibilities etc.

This study had some limitations. First of all, this research was conducted with limited number of participants due to COVID19 pandemic situation and this sample size might not represent the whole population of this study. As sample size was small in this study, researcher not found significant association of level of stress with all of the variables. If sample size were larger then association of level of stress with variables might be founded. Also, in this research there was only one study site from where all participant were nearly same sociodemographic conditions such as majority had same living area, socio economic status. By adding more study sites may differ the more socio demographic condition which may differ the stress level. Related articles were found but these were studied in the context of different countries so, no significant statistical result was included in this study in the context of Bangladesh.

Children with CP need excessive care in self-care activities than normal children. Critical limitations in self-care functions of the children with CP can be detrimental to the psychological well-being of their Mothers. Based on the result, it can be concluded that mothers of children with CP suffered high level of stress and their social participation are decreasing due to lack of accessibility in their living area, transport and market place. Mothers often play principal role in the treatment and rehabilitation of children with CP. If they stay in stressful situation for long period of time, it will be difficult for them to properly play their role in rehabilitation process of their children. So, health professionals should consider the psychological status of mothers and provide proper treatment or prevention to the stress of mothers for improving the rehabilitation process and achieve better resulting children.

Understanding the psychological impact of child's disability on mothers could enable healthcare providers to deliver support in a way that promotes optimal adjustment of the mothers to live with this problem. In current study, it was suggested that psychological support should include in intervention process by arranging any stress management program for the mothers with children with CP to ensure better outcome from rehabilitation program.

If any other researchers want to do this study further, they are recommended to increase the participants' numbers and study sites. Health care professionals are recommended to early identify the mothers who are at risk of poor mental health and provide psychological support to facilitate successful rehabilitation of children with CP. This study found that the mothers were suffering high level of stress. Organization can consider the stress of the mothers' and develop plan to provide stress management program.

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Appendix 1
Approval letter of IRB for conducting study



বাংলাদেশ হেল্থ প্রফেশন্স ইনস্টিটিউট (বিএইচপিআই)
Bangladesh Health Professions Institute (BHPI)
(The Academic Institute of CRP)

Ref:

CRP-BHPI/IRB/02/2021/440

Date: 04th February,
2021

To
Farjana Akhter
5th Batch (Part-II) M.Sc. in Rehabilitation Science (MRS)
Session: 2018-19, Student ID:181180113
BHPI, CRP, Savar, Dhaka-1343, Bangladesh

Subject: Approval of the thesis proposal "Stress level of mothers of children with Cerebral palsy" by ethics committee.

Dear Farjana Akhter,
Congratulations.

The Institutional Review Board (IRB) of BHPI has reviewed and discussed your application to conduct the above-mentioned dissertation, with yourself, as the Principal investigator. The following documents have been reviewed and approved:

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

The purpose of the study is to find out the stress level of mothers of children with Cerebral palsy. The study involves collecting information about social participation through face to face interview and measuring stress level using a standard questionnaire (Parental Stress Scale), which may take 15-20 minutes. There is 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 18th February 2019 at BHPI (20th IRB Meeting).

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,

Muhammad Millat Hossain

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

Appendix 2 Permission letter for data collection

Date: 08.02.21

To,
The In-Charge
Paediatric Unit
CRP, Savar, Dhaka.


Subject: Request for permission to collect data for research project


Sir,

With due respect, I Am Farjana Akter, final year student of Masters in Rehabilitation Science program at Bangladesh Health Professional Institute (BHPI) - an academic institute of CRP under Faculty of Medicine, university of Dhaka. This is a two-year full-time course under the project of "Regional Inter-professional Master's Program in Rehabilitation Science" funded by SAARC Development Fund (SDF). I have to conduct a thesis entitled, "Stress level of mothers of children with Cerebral palsy" under the guidance of Prof. Md. Obaidul Haque, Professor of Physiotherapy, Vice Principal, BHPI. The study involves use of standardized question for mothers of children with cerebral palsy that may take 15-20 minutes to collect the data. A written consent will be taken prior and assured that all the information given by the participants would be kept confidential and the participants can withdraw themselves at any time according to their desire. I would like to assure that anything of my research project will not be harmful for the participants.

I therefore pray and hope that you would be kind enough to grant me permission to collect data and useful information that I need for conducting the research and oblige thereby.

Sincerely Yours


Farjana Akter
Student of M.Sc. in Rehabilitation Science
Session: 2018-2019
BHPI, CRP, Savar, Dhaka-1343


8-2-21
Masnara Perveen
Head of Department
Department of Paediatrics
CRP Savar, Dhaka

Appendix 3 Consent Form in Bangla and English

সম্মতিপত্র

গবেষক, ফারজানা আক্তার, বাংলাদেশ হেলথ প্রফেশনস ইনস্টিটিউট এর ছাত্রী যা পক্ষাঘাতগ্রস্থদের পুনর্বাসন কেন্দ্র সি.আর.পি এর একটি শিক্ষা প্রতিষ্ঠান। তিনি মাস্টার্স ইন রিহ্যাবিলিটেশন সাইন্স প্রোগ্রামে অধ্যয়নরত। এই গবেষণাটি তার অধ্যয়নের একটি অংশ। গবেষণাটির শিরোনাম “ সেরেব্রাল পালসি আক্রান্ত শিশুর মায়েদের মানসিক চাপের পর্যায় ”।

গবেষণাটি অংশগ্রহণকারীদের উপকারে নাও আসতে পারে, তবে ভবিষ্যতে অংশগ্রহণকারীর মতো ব্যক্তিগণ গবেষণা থেকে উপকৃত হতে পারেন। গবেষক অংশগ্রহণকারীদের অনুমতি সাপেক্ষে সাক্ষাতের তথ্য সংগ্রহের জন্য মোবাইল ফোন ব্যবহার করতে পারবেন।

আমি গবেষণাটির উদ্দেশ্য সম্পর্কে যথেষ্ট অবগত হয়েছি। আমি যে কোন সময় যে কোন মুহূর্তে গবেষণা থেকে অংশগ্রহণ বাতিল করতে পারব এবং এর জন্য কারও কাছে জবাবদিহি করতে বাধ্য থাকব না।

আমি অবগত হয়েছি যে গবেষণার জন্য আমার দেয়া সব তথ্য নিরাপদ ও গোপন রাখা হবে এবং যদি প্রকাশনার কাজে ব্যবহার করা হয় তাহলে নামহীনভাবে প্রকাশ করা হবে। আমার নাম, ঠিকানা এই গবেষণায় কোথাও প্রকাশ করা হবেনা।

স্বাক্ষর

অংশগ্রহণকারীর স্বাক্ষরঃ	তারিখঃ
স্বাক্ষীর স্বাক্ষরঃ	তারিখঃ
গবেষকের স্বাক্ষরঃ	তারিখঃ

Consent form

The researcher Farjana Akhter, is a student of the Bangladesh Health Professions Institute (BHPI) which is the academic institute of the Centre for the Rehabilitation of the Paralyzed (CRP), Savar, Dhaka. She is studying in M.Sc. in Rehabilitation science. This study is a part of her course curriculum. The title of the study is, "Stress levels of mothers of children with Cerebral palsy". This study may not give any benefit or impact on participant work at present but in future people similar to them may get benefit from the study.

In this study I am a participant and I have been clearly informed about the purpose of the study. I will have the right to withdraw in taking part from the study at any time at any stage and I am not bounded to answer to anyone for this.

I also informed that, researcher will keep all my information safe and confidential and the identity of me and my child will not be disclosed in publication of the study. Personal identity such as participant's name and address will not be published anywhere of the study. I have been informed about the above-mentioned information and I am willingly agreed to be a participant of the study with giving my consent.

Signature:

Signature of the Study Participant:	Date-
Signature of the witness:	Date-
Signature of the Researcher:	Date-

Appendix 4

Socio-demographic questionnaire in Bangla and English

প্রশ্নাবলী

বিভাগ ক: সামাজিক জনসংখ্যা বিষয়ক প্রশ্নাবলী

১. অংশগ্রহনকারীর কোড:

২. বয়স:

৩. শিক্ষাগত যোগ্যতা:

- নিরক্ষর প্রাথমিক মাধ্যমিক
 উচ্চ মাধ্যমিক স্নাতক স্নাতকোত্তর বা ততোধিক

৪. বৈবাহিক অবস্থা:

- বিবাহিত অবিবাহিত তালাকপ্রাপ্ত বিধবা

৫. পেশা:

- শিক্ষার্থী গৃহিনী চাকুরীজীবী অন্যান্য

৬. বসবাসের স্থান:

- গ্রাম মফস্বল শহর

৭. সন্তানের যত্ন নেয়ার সময়কাল:

- ২-৫ ঘন্টা
 ৬-১০ ঘন্টা
 ১১ ঘন্টা বা তার উপরে

৮. সন্তানের সংখ্যা:

- ১ ২ ৩ ৪ বা ততোধিক

৯. আর্থ-সামাজিক অবস্থা:

- নিম্নবিত্ত (পরিবারের মাসিক আয় ৭,৫০০/= টাকার কম)
 নিম্ন মধ্যবিত্ত (পরিবারের মাসিক আয় ৭,৫০০/= থেকে ২৫,০০০/= টাকা)
 উচ্চ মধ্যবিত্ত পরিবারের মাসিক আয় ২৫,০০০/= থেকে ৫০,০০০/= টাকা)
 উচ্চবিত্ত (পরিবারের মাসিক আয় ৫০,০০০/= টাকার বেশি)

Part A: Socio Demographic Questionnaire

১. **Participants Code:**

২. **Age in Years:**

৩. **Educational Status:**

- Illiterate Primary Secondary
 HSC Bachelor Masters and above

4. **Marital status:**

- Married Unmarried Divorced Widow

5. **Occupation:**

- Student Housewife Service holder Other

6. **Living area:**

- Rural Semi-urban Urban

7. **Care giving duration:**

- 2-5 Hours
 6-10 hours
 11 hours and above

8. **Number of children:**

- 1 2 3 4 More than 4

9. **Socio Economic Status (SES):**

- Low SES (Family monthly income less than 7,500/= Taka)
 Lower Middle SES (Family monthly income 7,500/= to 25,000/= Taka)
 Higher Middle SES (Family monthly income 25,000/= to 50,000/= Taka)
 High SES (Family monthly income more than 50,000/= Taka)

Appendix 5
Parental Stress Scale (PSS) in Bangla and English

বিভাগ-খ- প্যারেন্টাল স্ট্রেস স্কেল

১ = দৃঢ়ভাবে একমত নয় ২ = একমত নয় ৩ = নিরপেক্ষ ৪ = একমত ৫ = দৃঢ়ভাবে একমত

১	মা হিসেবে আমি আমার নিজের ভূমিকা নিয়ে সন্তুষ্ট।	
২	আমার সন্তানের সামান্যতম প্রয়োজনেও এমন কোনো কাজ নেই যা আমি করবো না।	
৩	সন্তানের দেখাশোনার জন্য যতটুকু সময় ও শ্রম দেয়া যায় মাঝেমাঝে তার থেকে বেশি দিতে হয়।	
৪	আমার মাঝে মাঝে মনে হয় সন্তানের জন্য আমি যতটুকু করছি তা যথেষ্ট কিনা।	
৫	আমি আমার সন্তানের সাথে খুবই ঘনিষ্ঠ।	
৬	সন্তানের সাথে সময় কাটাতে আমার ভালো লাগে।	
৭	আমার সন্তান আমার কাছে গুরুত্বপূর্ণ স্নেহের উৎস।	
৮	সন্তান থাকায় আমি আমার ভবিষ্যত সম্পর্কে আরও সুনিশ্চিত ও আশাবাদী।	
৯	আমার জীবনের সবচেয়ে বড় দুশ্চিন্তার উৎস হলো আমার সন্তান।	
১০	সন্তান থাকায় আমার নিজের জীবনের সময় ও স্বাচ্ছন্দতা কমে গিয়েছে।	
১১	সন্তানের জন্য আর্থিক সমস্যার সম্মুখীন হতে হচ্ছে।	
১২	সন্তানের জন্য অন্যান্য দায়িত্ব পালন করতে সমস্যার সম্মুখীন হতে হচ্ছে।	
১৩	সন্তানের আচরণ প্রায়ই আমার জন্য বিব্রতকর অথবা মানসিক চাপের কারণ।	
১৪	আমাকে যদি পরবর্তীতে এই ধরনের সমস্যার সম্মুখীন হতে হয়, তবে আমি হয়তো আরও সন্তান না নেয়ার সিদ্ধান্ত নিব।	
১৫	মা হিসেবে আমি আমার দায়িত্ব নিয়ে আনন্দিত।	
১৬	সন্তানের জন্য আমার নিজের ইচ্ছাগুলো ও জীবনের প্রতি নিয়ন্ত্রণ কমে গিয়েছে।	
১৭	মা হিসেবে আমি সন্তুষ্ট।	
১৮	আমি আমার সন্তানের সাথে সময় কাটানো উপভোগ করি।	

Part B: Parental Stress Scale

1 = strongly disagree 2 = Disagree 3 = Undecided 4 = Agree 5 = strongly agree

1	I am happy in my role as a parent.	
2	There is little or nothing I wouldn't do for my child (ren) if it was necessary.	
3	Caring for my child (ren) sometimes takes more time and energy than I have to give.	
4	I sometimes worry whether I am doing enough for my child(ren).	
5	I feel close to my child(ren).	
6	I enjoy spending time with my child(ren).	
7	My child(ren) is an important source of affection for me.	
8	Having child(ren) gives me a more certain and optimistic view for the future.	
9	The major source of stress in my life is my child(ren).	
10	Having child(ren) leaves little time and flexibility in my life.	
11	Having child(ren) has been a financial burden.	
12	It is difficult to balance different responsibilities because of my child(ren).	
13	The behavior of my child(ren) is often embarrassing or stressful to me.	
14	If I had it to do over again, I might decide not to have child(ren).	
15	I feel overwhelmed by the responsibility of being a parent.	
16	Having child (ren) has meant having too few choices and too little control over my life.	
17	I am satisfied as a parent.	
18	I find my child(ren) enjoyable.	

Appendix 6

Questions about social integration in Bangla and English

বিভাগ-গ সামাজিক একীকরণ প্রশ্নসমূহ

১. আপনি আপনার সন্তানকে নিয়ে বিভিন্ন সামাজিক কার্যক্রমে অংশ নিতে পারছেন?
 হ্যাঁ না
২. সন্তানকে বহন করা আপনার শারীরিক কষ্টের কারণ হয়ে দাঁড়ানোর কারণে আপনি কি কোনো সামাজিক অনুষ্ঠানে অংশগ্রহণ করতে আগ্রহী নন?
 হ্যাঁ না
৩. সমাজের মানুষদের নেতিবাচক দৃষ্টিভঙ্গির কারণে আপনি কি সামাজিক অনুষ্ঠানগুলোতে অংশগ্রহণ করতে আগ্রহী নন?
 হ্যাঁ না
৪. আপনার আশেপাশের বা সমাজের লোকজন কি আপনার প্রতি সহযোগিতাপরায়ন?
 হ্যাঁ না
৫. আপনি কি আপনার সন্তানকে নিয়ে বিভিন্ন প্রয়োজনে ও কেনাকাটা করতে বাইরে যেতে পারছেন?
 হ্যাঁ না
৬. আপনি কি আপনার সন্তানকে নিয়ে বাজার অথবা শপিংমলগুলোতে সহজে প্রবেশ করতে পারেন?
 হ্যাঁ না
৭. আপনি কি আপনার সন্তানকে নিয়ে সামাজিক কার্যক্রম, কেনাকাটা অথবা কোনো প্রয়োজনীয় কাজে ঘরের বাইরে চলাচলের ক্ষেত্রে অনুপযুক্ত বসবাসের পরিবেশের জন্য সমস্যার সম্মুখীন হন?
 হ্যাঁ না
৮. গনপরিবহনে (বাস, কার ও অন্যান্য) চলাচলের ক্ষেত্রে আপনি কি কোনোদিন কোনো সমস্যার সম্মুখীন হয়েছেন?
 হ্যাঁ না
৯. আপনি কি আপনার সন্তানকে নিয়ে যাতায়াত করার জন্য গনপরিবহনগুলোকে (বাস, কার ও অন্যান্য) উপযুক্ত বলে মনে করেন?
 হ্যাঁ না
১০. আপনার কি ইদানীং বন্ধুবান্ধব বা আত্মীয়দের সাথে সুসম্পর্ক বজায় রাখতে কোনো সমস্যা হচ্ছে?
 হ্যাঁ না
১১. আপনি কি সমাজের অন্যদের থেকে নিজেকে বিচ্ছিন্ন মনে করেন?
 হ্যাঁ না

Questions about social integration

1. Can you participate in social functions with your child?
 Yes No
2. Aren't you interested to participate at any social functions because of the physical burden to carry your child?
 Yes No
3. Aren't you interested to participate at any social events because of the negative attitude of the community people?
 Yes No
4. Are the people of your community or society supportive to you?
 Yes No
5. Can you frequently go outside for shopping or any other necessary activities with your child?
 Yes No
6. Do you have accessibility in market or shopping malls with your child?
 Yes No
7. Do you face difficulties to go outside with your child for attending any social function, shopping or any other necessary activities because of poor accessibility in your living environment?
 Yes No
8. Do you find lack of options of public transport (Bus, cars, others) anytime?
 Yes No
9. Do you have accessibility in Public transports (Bus, Cars, others) with your child?
 Yes No
10. Do you think you are having problems maintaining relationships with your friends and relatives these days?
 Yes No
11. Do you feel isolated from others of your society?
 Yes No