

**PARENTS PERCEPTION OF CEREBRAL PALSY CHILD AFTER  
CONFIRMING THE DIAGNOSIS**

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

**PARENTS PERCEPTION OF CEREBRAL PALSY CHILD AFTER  
CONFIRMING THE DIAGNOSIS**

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**Declaration**

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

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## **Acronyms**

- ADL's:** Activities of Daily Living
- BHPI:** Bangladesh Health Professions Institute
- CP:** Cerebral Palsy
- CRP:** Centre for Rehabilitation of the Paralysed
- QOL:** Quality of Life
- WHO:** World Health Organization
- IRB:** Institutional Review Board
- BMRC:** Bangladesh Medical Research Council

## Abstract

**Purpose:** Cerebral palsy is a common condition in Bangladesh which causes childhood disability. In most cases the parents are the primary caregiver for their child with cerebral palsy. Parents face many problems when caring her child and cope as best as they can.

**Objectives:** To identify the parents perception of the cerebral palsy child. The objectives of the study is to find out the parents perception of the cerebral palsy child after confirming the diagnosis. **Methodology:** Qualitative methodology was used to conduct this study.

Participants for this study were the parents of children with cerebral palsy who are taking treatment in CRP. For data collection 14 parents were purposively selected and in-depth interview was conducted with a semi-structured open-ended questionnaire. Then the data was analyzed using qualitative content analysis. **Results:** The parents interviewed reported that parent's perception of cerebral palsy child. Communication with parents who are confirming the diagnosis of their child's that their child are affected by cerebral palsy. So, it is a difficult task for professionals. Parents are experiencing great emotional stress during the diagnostic process and dissatisfaction with disclosure is widespread. The aim of this study was to investigate parents' perceptions when realizing their child's disability, the impact of the diagnosis and find out the perception of parent's social life, relationship status, physical health condition and economical status.

**Key Words:** Cerebral palsy, Quality of life, Perception.

**1.1 Background**

Bangladesh is one of the densely populated countries in the world. Disability is a major social and economic phenomenon in the country. In this country, disability is the most challenging issue. Cerebral palsy is the most common condition that is responsible for the child disability. A child is born in family as the torch bearer, but when it is born with any disability then it bears curse for its family, even the parents are treated as the results of great sin. Now-a-days, this thinking has been changed enough in most of the countries of the developed world, but some developing countries like Bangladesh yet now is not enough aware of disability.

In childhood there are numerous maladies are influenced among them Cerebral palsy (CP) who is the most common motor infection. Cerebral paralysis is a central nervous system clutter that is went with by unsettling influence of sensation, perception, communication, cognition, epilepsy and musculoskeletal disorders (Hwang et al., 2011). It is (CP) a complex neurodevelopmental disorder and is the driving cause of physical inability in childhood (Rosenbaum et al., 2007). Children with Cerebral paralysis display with essential development challenges but can moreover have a wide run of accompanying disarranges that affect their life and working, such as epilepsy, tactile and perceptual disarranges, and learning, communication, and behavior troubles (Rosenbaum et al., 2007). Cerebral palsy is a common term utilized to depict a bunch of complex formative disarranges. In childhood we know, Cerebral palsy is the most common physical inability and the primary cause is obscure. The term ‘Cerebral palsy’ characterizes a group of disorder of development and posture due to a deformity of the immature brain. Cerebral palsy is a symptom complex with different types and degree of motor disability. These disorders gotten to be checked early in life and are lasting and non-progressive condition (Reddihough & Collins, 2003).

Cerebral paralysis (CP) is a shape of brain harm that can seriously influence motor control, co-ordination, discourse and complex thought. In most cases, CP creates during pregnancy since of a few injury that harms the brain in-utero. Roughly 10 to 20% of children with

cerebral paralysis obtain it after birth, regularly from brain harm maintained in the to begin with few months or a long time of life. In such cases, the disorder may result from brain diseases like bacterial meningitis or viral encephalitis, or from head injury maintained from a mischance, drop, or incurred injuries like the shaken child disorder. Be that as it may, in numerous times no particular cause can be distinguished (Dumas et al., 2008).

Cerebral paralysis is a driving cause of physical inability in childhood with 90% of influenced children supporting harm or deformity to their creating brain during the antenatal period (Pruitt et al., 2009). It is one of the most common extreme physical incapacity among children and 3rd most common major formative incapacity and mental retardation (Begum & Desai, 2010). In spite of the fact that the impaired motor work is a trademark of the CP, numerous children moreover involvement of wellbeing, tactile and perceptual troubles and may have complex restrictions in self-care capacities, such as nourishing, dressing, washing, and mobility capacities (Baltor & Dupas, 2013). It is a condition caused by unusual arrangement of brain that limits motor work, mental and behavioral capacities of the children. They have dangers for seizures, troubles in cognitive capacities, behavior, learning and feeling. These troubles regularly impact the necessities of long term care and have an effect on the quality of life of guardians particularly mother (Krstic et al., 2012). So, birth of a CP child is one of the terrible occasions in the life of any couple. This occurrence could impair their mental and physical wellbeing (Rezvani et al., 2014).

The side effects of cerebral paralysis incorporate: over the top dribbling, trouble swallowing, sucking or talking, tremors, and trouble with fine motor skills such as securing buttons or holding a pencil, firm or tight muscles, low muscle tone, overstated reflexes, uncontrolled body development, toe strolling, limping or dragging a foot while strolling, strolling with a scissor stride, turning in their legs as they walk. Children with cerebral paralysis can moreover have nourishing issues, mental retardation, seizures, learning disabilities and issues with their vision and hearing. The side effects don't compound with age but side effects can extend from mild to extreme (Iannelli, 2008). Drooling is another but common indication among children with CP. The predominance has been appeared

from 16.8% to 58%. Visit drooling may cause skin laceration and disease, body liquid loss, and repetitive pneumonia. At school and at domestic, children with salivary discharges may cause harm to books, educating materials and furniture, and it indeed interferes with social connections. It is educated that children with CP that drool are frequently maintained a strategic distance from by other children, and recognizable and new grown-ups. The drooling in children with CP could influence with increment their subordinate level of care of everyday living and their instructive level. A few considers advice that drooling might be related with a decreased quality of life among children with CP (Chang et al., 2012).

Signs can show up during a few stages of early life. They incorporate: neonatal – early Earliest stages (0-3 Months): high pitched cry, poor neck control, over the top lethargy or irritability, powerless suck or tongue pushed or tonic bite, verbal extreme touchiness, diminished interest in environment, solid or floppy pose, abnormal or delayed reflexes. Afterward infancy-inability to perform motor abilities control of hand get a handle on by 3 months, rolling over by 5 months and autonomous sitting by 7 months. Anomalous formative designs: hand preference by 12 months, over the top curving of back, delayed or unusual parachute reaction, and logrolling. Irregular formative designs after 1 year of age: W sitting implies both knee flexion, legs amazingly turn, foot rearranging implies hurries along the floor, tiptoe walking or jumping (Gershon et al., 2013).

The first responses of guardians after a incapacity diagnosis of their children, they are gotten to be sense of bad form, hatred against destiny, faulting each other and gotten to be disillusioned (Hung et al., 2010). Parents who have such children may suffer from different conditions such as depression, anxiety, anger, fear, shame and desire to die (Rezvani, 2014). But children's common enhancement specifically related to caregivers commitment and concern (Marx, 2011). For a child, care-giving plays an critical part but giving the care for a child with long-term useful restrictions is totally distinctive and it has a negative effect on guardians particularly mother in terms of requests on physical wellbeing, disturbed rest, trouble in keeping up social connections, weight on conjugal connections, economical burden may increments day by day (Khayatazadeh et al., 2013). Parents of children with CP have lower quality of life and high level of sadness, anxiety (Sajedi et al., 2010).

In Australia, CP happening in roughly 2 to 2.5 per 1000 live births which is the primary cause of physical incapacity in children. There has been total intrigued in the quality of life of children with CP in later a long time (Davis et al., 2009). In USA, caregivers of children with CP may be beneath more physical, mental, and money related burdens compared with those who give care for children who create in a normal way since their duties are more prominent. In expansion to giving coordinate every day care and back, caregivers of children with CP contribute time and exertion in helping with intercessions such as physical, word related, and discourse treatment. In this way recognition of caregivers' or guardians almost their child's needs and endeavors related to the everyday care of their children likely to have considerable effect on the choice and victory of the child's rehabilitative administration (Hwang et al., 2011). In UK, one in five children with CP (20.2%) was found. They had a separate mental shortage and were incapable to walk. Among those babies birth weight is less than 1500g, the rate of CP was more than 70 times higher compared with those weight is 2500g or more at birth, the rate of CP rose during the 1970s, but remained steady during the late 1980s (Johnson, 2002).

In the meantime, it is vital to keep in mind that each child with CP is distinctive and will have claim set of inabilities and impediments to overcome the circumstance. As a result, a one of a kind instruction program will require to be planned for children and give to each child's person needs. It is too critical for guardians to work with their children at domestic and actualize the same standards so they can learn and develop in each perspective of their lives (Dumas et al., 2008). In spite of the fact that numerous ponders have tended to child rearing intercessions for CP children, still more investigate is required in this zone (Whittingham et al., 2011).

Cerebral paralysis is treated by Pediatric physiotherapists and they work multi-disciplinary group approach in CRP. Physiotherapist's employments combination of treatment are Neurodevelopment Treatment, Tactile integrator treatment and Proprioceptive Neuromuscular assistance (Mahmud, 2003). Parents in our consider felt sad when doctors uncovered their child's conclusion and guess as exceptionally serious, without giving any positive data. Trust is a critical propelling figure for guardians in looking for treatment for

their child and making a difference them to overcome their negative feelings (Graungaard & Skov, 2006). One inquire about pointed out that revelation without positive data leads to disappointment with a physician's heartless state of mind, caring, and support (George et al., 2007).

After all, parents had paradoxical feelings, experiences about the diagnosis. They had feared that there was something wrong with their child, yet felt a sense of release after confirming the diagnosis of cerebral palsy. The diagnosis confirmed long-held confusions about their child's developmental delay. However, it was hard to accept the diagnosis at that moment, because it destroyed their hope of being a parents of a healthy child. This perception damaged their self-concept as a parents and their relationships with their family.

## **1.2 Rationale**

Cerebral palsy is a common condition, mostly seen in developing country. Day by day there is increasing the number of cerebral palsy patient, in different areas. As Bangladesh is a developing country and trying to develop health care system so it is important to know the study will create and overview about demography of cerebral palsy. Physiotherapy is a significant part of this multi-disciplinary team. As the physiotherapy profession is newly introduced in Bangladesh, many people are not aware of its purpose. But it is an important part of health care to prevent diseases as well as to improve or maximize independence in people with disabilities. Therefore, physiotherapy can play an absolute role in preventing Cerebral palsy and aware the people about it which is essential to strengthen our profession. It generates exact information considering detail about which causes, occupation, age, gender, diagnosis, and duration. This study is about the parents overall perception such as education, physical health and self-care functions of cerebral palsy child. It helps to know the positive or negative perception of parents about their cerebral palsy child.



### **1.3 Research Question**

What is the perception of parents about their cerebral palsy children after confirming the diagnosis?

## **1.4 Objectives of study**

### **1.4.1 General objective**

To find out the perception of parents about their children with cerebral palsy after confirming the diagnosis.

### **1.4.2 Specific objectives**

- To identify the parents perceptions about the knowledge& the condition of cerebral palsy.
- To identify the amount of time parents can spend to perform their ADL's (self-care, productivity, leisure) along with taking care of their cerebral palsy child.
- To identify the perception of parents if they facing any challenges (physical, family, social and psychological) for a child with cerebral palsy.
- To identify the parents perception about their relationship and economic status.

## **1.5 Operational definition**

### **Cerebral palsy**

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

Cerebral palsy precisely implies brain loss of motion (Alvarez, 2013). ‘Cerebral’ alludes to the brain and ‘Palsy’ to a disorder of development or weight. In case somebody has cerebral paralysis it implies since of a damage to the brain (cerebral) he or she is not able to utilize a few of the muscles of body in typical way. CP is a gather of condition that influences the development and pose of body. Cerebral palsy is the most common neurodevelopmental motor inability in children. The condition requires therapeutic, instructive, social, and rehabilitative assets all through the life expectancy (Hurley et al., 2011). Brain structure harm is irreversible and lasting. And the indications are variable that changed over time. Children have development and postural disorder related with numerous inabilities such as- counting mental inability, hearing and visual shortages, nourishment, nourishing and swallowing issues, respiratory diseases and epilepsy. Cerebral palsy endures for long term and it influence exercises of everyday living and quality of life (Bell et al., 2010).

Agreeing to the Observation of CP in Europe (SCPE) definition, cerebral palsy is a gather of lasting and non-progressive disorders of development and pose caused by a central nervous injury, harm or brokenness starting early in life (Elkamil et al., 2011). Cerebral paralysis incorporates a gather of lasting disarranges of development or posture caused by an early brain damage. In spite of the fact that a few variables counting preterm birth and low birth weight for development are related with overabundance hazard, the causes of cerebral palsy stay to a great extent obscure. Pre-eclampsia influences 3-5% of pregnant ladies and is characterized by maternal hypertension and proteinuria happening after 20 weeks of incubation. Genuine signs may actuate iatrogenic preterm conveyance and preeclampsia contributes considerably to rashness, perinatal dismalness, and mortality. Early onset pre-eclampsia is commonly related with serious placental brokenness, which can compromise fetal blood supply and cause fetal development limitation, constant hypoxemia and conceivably brain harm. Consequently it is conceivable that pre-eclampsia could be a chance calculate for cerebral paralysis (Melheim et al., 2013).

Cousin marriage is one of the capable happening for cerebral palsy. Since cousins have one or both grandparents in common and on the off chance that either of the two grandparents, maternal or fatherly carries an imperfect recessive quality, it stands a great chance of getting to be homozygous in any one child who is an item of such consanguineous 9 relational unions (Islam & Ahmed, 2009). The hazard of neonatal are expanded in white matter harm and afterward motor, cognitive, and behavioral disabilities while babies born at exceptionally low gestational ages. The low gestational age and cerebral white matter harm lead to preterm birth can harm the creating brain. The pregnancy disorder is moreover potential figure for harming the creating brain. Cranial ultrasound injuries was showed that moreover causes CP analyzed afterward (McElrath et al., 2009). Cerebral palsy is a long term condition and most common physical disability in childhood. In adulthood children with cerebral palsy is poorly understood and usually survive.

Cerebral palsy is the most common persistent motor disorder of childhood, influencing roughly 2 to 2.5 newborn children per 1,000 live births. The increment in survival rates for preterm newborn children has increased the chance of brain wounds that possibly cause CP. In expansion to unlimited wellbeing, social, and mental issues that the influenced children and their families endure CP has a tremendous financial affect (Faria et al., 2011). In created nations, worldwide appraisals propose that CP influences between 1.2 and 3.0 per 1000 children (Hustad et al., 2011). In the Norwegian provinces there were 494 children with CP born between 1st January 1996 and 31st December 2003, comparing to a predominance of 2.65 per 1000 live births (Elkamil et al., 2011). In Joined together States, the particular predominance of CP is questionable since steady data is missing on follow-up of a whole population. Larger part of births particularly include for term and late pre-term newborn children. In the Joined together States assessed a predominance of 3.6 cases per 1000 children at eight a long time of age where a population consider was appeared, utilizing information from three regions but the study between children with and without a history of prematurity did not recognize (Miller, 2013). The United States appears that CP may influence up to 3.6 per 1000 children in another consider (Hustad et al., 2011).

In Canada, CP increments predominance transiently may be expected given the huge decreases that have been identified in neonatal and newborn child mortality rates. It is not shocking to watch increments in populace rates of CP and other inabilities, particularly exceptionally preterm newborn children, surviving past earliest stages with more newborn child. Other hand different births and preterm births, have expanded, which is the higher rates of CP. We subsequently, conducted a population-based study to assess transient changes in the predominance of CP and the rate of newborn child passing in a birth cohort of 24- to 30-week newborn children who were born between 1993 and 2002 (Vincer et al., 2006). In recent years, the predominance of CP has been reliably anticipated at 2.0 to 2.5 cases per 1000 live births. These estimates turn into 15,000 to 20,000 children with CP in Canada and 1,50,000 in the Joined together States, that the enormous larger part of whom are cared for at domestic by their guardians and families (Brehaut et al., 2004). A study in UK appeared that predominance rates varies from 1.5/1000 live births to 3/1000 live births (Johnson, 2002). Disability in a child coming about from CP not as it were influences the child's life but moreover the family's life. Regular issues in caring for a child with disabilities are troublesome. The guardians and other individuals of family, relatives and indeed neighbor's involvement push to a variable degree. Children with disabilities for the most part live in creating nations. In creating nations the larger part of families are as of now living beneath troublesome conditions with few assets and small get to suitable 3 administrations. The predominance of disability in a population of children ages 2-9 a long time from both urban and country populations was assessed to be 70/1,000 for all grades of seriousness and 22/1,000 for genuine incapacity in Bangladesh (Mobarak et al., 2000). Study appears that cerebral paralysis rates change among populations in connection to age, sexual orientation, race, conjugal status, occupation and contrasts in transient or natural conditions (Kasiulevicius et al., 2006).

Learning of a child's diagnosis of disability has long been respected as an emergency for guardians (Hatton et al., 2003). Their responses incorporate shock due to misfortune of their desires of a solid infant, dissent and refusal to acknowledge the determination, anger and accusing the therapeutic framework for destitute quality treatment, fear and instability around the degree or degree of inability and related disability (George et al., 2007), and feeling disempowered and overpowered by an unusual future (George et al., 2007). These

findings are based on studies conducted with guardians of cerebral paralysis child's. In spite of the fact that a few common encounters apply to guardians of cerebral paralysis child's, the special impact of culture and the conventional family are not well caught on. As nations such as the Joined together States of America (U.S.A) and the Joined together Kingdom (U.K.) have ended up more multicultural, with huge and developing Asian populations (Hayes et al., 2008). It is vital for healthcare experts in numerous nations to get it superior how guardians involvement a child's diagnosis of disability, affected by family and culture. The predominance of disability of direct and extreme is evaluated to be 5% in children matured 0–14 a long time. In low-income nations inability among children is more common than high-income nations (Kawakatsu et al., 2012).

Children with cerebral palsy require additional care and support from their family. But behavior of child and burden of ordinary caregiving of child make numerous issues of mother in their everyday living exercises (Mobarak et al., 2000).The injury and damage to the brain is permanent in cerebral palsy. The brain does not “heal” as other parts of the body might. Because of this, the cerebral palsy itself will not change for better or worse during a person's lifetime. On the other hand, associative conditions may improve or worsen over time. The effects of cerebral palsy are long-term, not temporary. An individual diagnosed with cerebral palsy will have the condition for their entire life. Birth of a cerebral palsy child in a family, usually becomes a stressful event for the family. Parents are the main care-giver of cerebral palsy child and they have to manage burden of their own family responsibilities as well as care-giving needs related to the child with cerebral palsy. Cerebral palsy affects the other vital functions that also involve motor skills and muscles such as breathing, bladder and bowel control, eating and learning may also be affected when a child has CP.

There are different complication cerebral palsy such as cognitive disability, visual deficiency and hearing misfortune to disability of brief term memory, strabismus, language delays, learning challenges and behavioral disorder (Ballot et al., 2012).Parents who have children with cerebral palsy means how parents are passing their everyday life along with their special children. Parents are often sacrifices their own personal well-being in order to spend extended amounts of time to care for their children. They are always face different

problems in different way. Sometimes they become unconscious about their own live and due to surrounding difficulty they remain in stress and anxiety and that has an adverse effect on their quality of life. In the study, researcher wants to find out parents physical, psychological, family and social perception that they faced due to having a cerebral palsy child and the amount of time they can spend in performing ADL's with taking care of their child.

Agreeing to Mohammadi et al., (2014), quality of life of the person is characterized by WHO(World Wellbeing Organization) "The acknowledgment, the person pick up from their position in their live in the terms of their culture, values frameworks in which they live, objectives, desires, guidelines and position". The guardians with cerebral paralysis children, particularly the moms have to spend huge sum of time and vitality to take-care of their cerebral paralysis child, subsequently their person desires and measures would not be realized as a result, it influences their quality of life. Mothers' are ordinarily affected in all spaces of quality of life after having a child with cerebral paralysis. Maternal care-giving burden and unfavorable QOL is as a rule happens due to need of useful freedom, maladaptive behavior of the child with cerebral paralysis (Mohammadi et al., 2014). Physical, mental and social spaces of wellbeing are included in QOL as it is a multidimensional concept. When a child is analyzed with cerebral paralysis, it regularly makes incredible burdens on the family and they have to alter their everyday lives in expansion to oversee the distinctive and challenging behaviors of the child (Kheir et al., 2012).

In numerous research analysts detailed that parents of children with cerebral palsy confronted diverse psychosocial issues like push, discouragement, anxiety, limitations of movement, and strain in conjugal connections and reduced physical wellbeing. QOL of guardians who have children with cerebral paralysis implies how guardians are passing their ordinary life along with their extraordinary children. Guardians are frequently sacrifices their claim individual well-being in arrange to spend amplified sums of time to care for their children. They are continuously face different issues in different way. In some cases they ended up oblivious approximately their possess live and due to surrounding trouble they stay in stress and anxiety and that has an unfavorable impact on their quality of life. In the consider, analyst needs to discover out guardians physical, mental, family



and social issues that they faced due to having a cerebral palsy child and the sum of time. Raising a cerebral palsy child is exceptionally challenging for each parents specially mothers (Kheir et al., 2012).

It moreover exceptionally barely detailed that taking care of those children is profoundly challenging and unpleasant for guardians. Be that as it may, it takes a few times for a unused born child to alter with modern circumstances but in case of child with inability and uncommonly cerebral palsy child the circumstance gotten to be more troublesome since they appear abnormal social behavior and trouble in communicating in the society. After having a child with cerebral paralysis the ordinary elements of a family gotten to be changed since parents require to provide parts of time to take care of the uncommon child that's why parents feel troubles. Mothers take the major care-giving duty of the child and that's why they are more helpless in this point of view (Hartmann, 2012). Mothers have to endure more care-giving burden or may be than father (Abou Dagga, 2013).

Now-a-days parents are keeping up various parts and including themselves in work segment but due to larger part of childcare duties, they may be most affected by having a child with extraordinary needs. Care giving is an ordinary duty of parents but a cerebral palsy child is required high level of care which has a burdensome impact on the ordinary lives of mothers counting physical, mental and social. They can't use time for their recreation and involvement altogether more unpleasant occasions than mothers of regularly creating children since of more care-giving obligation (Mann, 2013). Parents exhaust huge sum of time with their children hence it prevents their conceivable outcomes to work exterior for contributing to preserve family costs. Some of the time guardians too take off their work for taking obligations of the special child. In case of Turkey parents lose their occupations and ordinarily work part-time since they are the as it were capable for taking care of the special children. On the other hand, guardians too have to spend a huge amount of time for getting therapeutic care for their children with cerebral paralysis that takes additional time and influencing their business status. Some of the time guardians gotten to be heartless almost their possess day by day life exercises to fulfill the needs of their special child. At long last, guardians have a lot of challenges in ADL's that influences their mental perspectives (Karasavvidis et al., 2011).

Parents of children with cerebral palsy are continuously remaining in stress. They have to face tall levels of child rearing stress, depression, and anxiety (Elfert, 2014). Parents of children with cerebral palsy stay in more stress or maybe than mothers with non-cerebral palsy child. They ordinarily stay in stress due to child's maladaptive behavior, need of instructive openings and dull future. This continuous stress has effect on parent's wellbeing. Destitute mental wellbeing and lower level of well-being of guardians is primarily happens for strongly sadness and stress. Be that as it may, parents have to face different mental wellbeing issues (Martins et al., 2013).

Parents of children with disabilities have experienced distinctive mental sickness issues (Dehnavi et al., 2011). Guardians have to oversee their child's challenging behavior, physical inabilities, failure to perform everyday living abilities, rest issues, eating unsettling influences, those are exceptionally time expending and in this way parents' become focused. In addition in Canada, mothers are experienced high level of stress than father (Ogston-Nobile, 2014). Mothers are profoundly included in child raising at that point father that's why it may be the reason of lift stress on mother. On the other hand, mothers are not sufficient mindful around the reason of their children's disability in this manner they emphatically feel blameworthy on themselves for their children's disability (Elfert, 2014). Many parents reported that they often feel intense anger, guilt, depression and anxiety. They feel helpless. They are found low on ability to cope by maintaining their social system, self-esteem and psychological and physical stability. Parents have to maintain high level of responsibility and have to spend lots of time with her special child that's why they always remain in mental stress that often affects their physical health.

Stress can become cause of numerous physical issues like migraines or backaches, muscle pressure and firmness, obstruction, sickness, dizziness, sleep deprivation, chest torment, and fast pulse, weight pick up, misfortune of sex drive, visit cold, need of insusceptibility and other wellbeing complications. Another study has detailed that mothers have mental trouble due to burden and stress of duty of their special children and this ordinarily influence the physical wellbeing. By and large like other sorts of disabilities a mother with extremely introverted child feel more stress (Abu-Dagga, 2013). Physical health problems are more common in case of mothers with cerebral palsy children than mothers of non-

cerebral palsy children. Parents have to spend high amount of time with their child with cerebral palsy to provide extra care and manage their challenging behavior that's why it creates an impact on their relationships with spouse and siblings. They often need extra close supervision from care-giver and also need to provide specialized medical care, and therapeutic interventions.

Mother as an essential caregiver, have to donate much exertion to fulfill the additional needs for their child with cerebral palsy and make adjust between the requests of cerebral palsy children and other non-cerebral palsy children. Now and then parents can't give sufficient care towards the other child due to her child with cerebral palsy (Petrongolo, 2014). In some cases parents face challenges to adjust time between their other children and cerebral palsy children and that's why the siblings may feel that they are overlooked or less vital for parents (Bashir et al., 2014).

Siblings feel envious towards their brother/sister analyzed with cerebral palsy since a huge amount of time parents spend with them. This behavior by siblings can make issues in family and make troubles for mothers as they are as of now passing through injury and stresses. This is an effect on relationship of mothers with their other children. Not as it were sibling's relationship now and then conjugal relationship is too affected in a few cases (Hartmann, 2012). Mothers are-giving part moreover influence their conjugal relationship. Parents of children with disabilities have experienced more conjugal stress than guardians with ordinary children, it is due to fulfill the additional requests of a cerebral palsy child, parents can't get sufficient time to spend individual time as a result issues makes in relationship between parents, they stay discouraged, and indeed it may leads to happen separate (Bashir et al., 2014). The predominance of separate is essentially higher in case of parents of children with cerebral paralysis. In Asian culture, some of the time father's inclusion in care-giving of the special child is less at that point mothers so that mothers become disappointed. In addition, mothers have too confronted distinctive problems from society individuals as well. They moreover have negative state of mind towards those children's and their mothers (Elfert, 2014).

A social life is the time people spend outside their own life, inside other peoples. People mostly have a social life during weekend when they have finished their routine jobs. Social

life is also what people celebrate, what they eat, what kind of music they listen to, etc. It combines various components: activities, people, and places. While all of those components are required to define a social life, the nature of each component is different for every person, and can change for each person, as affected by a variety of external influences the term social refers to a characteristic of living organisms. It always refers to the interaction of organisms with other organisms and to their collective co-existence. So social life is not something planned. It could be considered to be anytime we have interacting with other people in our lives. That can be at work, on the bus, buying sandwiches for lunch, at any events we go as well as social events.

Mothers of children with a disability have extra caregiving duties but get small extra support from their spouse or from expanded individuals of the family (yousafzai et al., 2011). So caring for child limit suddenness of mother and this need of suddenness limits regular activities of mother and in numerous ways disconnects mothers from their community. In numerous occasions mothers have intentioned limited their social intelligent in arrange to meet caregiving requests (Kishore, 2011). Mothers too recognized the more extensive community frequently recognize them contrarily and were stigmatized and faulted for having a child with a disability (yousafzai et al., 2011). A few individuals of the community still accept that children with disabilities are dishonorable or humiliating to the family and ought to be covered up from other individuals. In a few cases children are mishandled by peers. These states of mind result in children being separated from others (Hartley et al., 2005). When mothers go exterior the home with their child the state of mind of others hurt their nobility so mothers withdraw from social engagements (Huang et al., 2012).

The term 'relationship' is rooted from the word 'relation' and is defined as a mutual affiliation or connection between individuals or groups of people or entities. A relationship is a connection between two or more people or entities by affinity or kinship who share common connections, ideas, interest, feelings, beliefs and the like. Relationships are highly special and valuable and are necessary as human are social beings and do not live in isolation or vacuums and are interdependent on one another for many things. Relationships are associated with life and living, man/woman is inherently a social animal and

relationships are most important to him/her and he/she cannot live normally outside of a web of relationships. No one can exist without at least one relationship. Relationships can be family relationships between husband and wife, brother and sister etc.

A noteworthy issue for the mothers of children with cerebral palsy is destitute connections with parent-in-law and spouse since numerous of them thought that giving birth to a child with CP can bring social shame and disgrace (Huang et al., 2012). Mothers felt harmed, defenseless and powerless when their children were marginalized since of their inability, there was incredible trouble when parents-in-law accepted that the child caused them to lose face and set a burden on the whole family. In most cases mother was as it were capable for caring their child so mother was cleared out to bear all caregiving duties alone (Hartley et al., 2005). Keeping up a adjust between diverse roles made pressures of mother and adjusting the role as caregiver for giving domestic treatment and the part as a parent made harm on family relationship (Huang et al., 2012). In a few cases the mother was faulted for their child's disability and it was respected as women's discipline from their relatives. Negative states of mind of relatives and individuals of the community towards the mother too make destitute relationship between mother and their relatives (yousafzai et al., 2011).

Family is the basic and important unit in any society and children are central part of family. When a child born in a family the role of parents is also become changed. The birth of a child is normally an eager expectation for parents. Parents always expect a healthy baby who will give lots of happiness and peace. However, when a child born with a physical disability or a developmental disability, parents become shocked, anxious and also become frustrated for the child's early recovery. It is really an unexpected event for parents. After having a child with disability, it has a strong impact on the lives of parents. Cerebral palsy is one kind of complex developmental disorder rather than from other kinds of disability of children. After having a child with cerebral palsy the life of parents specially mothers become more stressful. They faced numerous challenges after having a child with cerebral palsy. Moreover, society and community people are not enough aware about this disorder and this is a matter of regret now-a-days.

### **3.1 Study Design**

Qualitative research is an orderly logical request which looks for to construct an all-encompassing, generally narrative, description to illuminate the researcher's understanding of a social or social phenomenon (Astalin, 2013).

The design has used to focus on the parents perception of cerebral palsy child. It also helps to identify the beliefs people hold and the perception of them from different perspectives. The researcher thought that this design was appropriate for this study because the parents of children with cerebral palsy are a specific group of in society and the study aim is to explore the perceptions of parent's with cerebral palsy children. The researcher collected the Information of participant's opinions because each participant's opinion is unique.

### **3.2 Study Site**

The study area for this study was pediatric unit of the Centre for the Rehabilitation of the Paralyzed (CRP). This setting was chosen for study area because many children with cerebral palsy go there with their parents to receive treatment. As participants were gotten in that setting who fulfilled the aims of the study so pediatric unit of CRP was selected for the study site.

### **3.3 Study Population**

Parents of cerebral palsy child at Centre for Rehabilitation of the Paralyzed (CRP)

### **3.4 Sampling Method**

The samples were selected by convenience sampling method.

### **3.5 Inclusion Criteria**

- Mothers or fathers of children with cerebral palsy who are interested to participate this study.
- Parents who have minimum primary education.
- Parents who are willingly interested to participate.
- Participants who are able to communicate and had no hearing problems will be selected for the study. Clear communication is required to provide answer during the interview session.

### **3.6 Exclusion Criteria**

- Parents of children without cerebral palsy.
- Unwilling parents
- Illiterate parents

### **3.7 Sample Size**

The participants were the parents (10 mothers or fathers) of children who have cerebral palsy and who are taking treatment from the pediatric unit of CRP at Savar.

### **3.8 Data Collection Tools**

For collecting data some other materials were also used. Tools or materials that was used for data collection are-

- Semi-structure open ended questionnaire
- Mobile tap-recorder
- Paper
- Pen
- Clip board
- Consent form

### **3.9 Method of Data Collection**

Data were collected by conducting face to face interviews providing a semi-structured questionnaire form.

### **3.10 Data Collection Procedure**

Semi-structured interview questions were used in this study. The interview was recording using a tape recorder by taking permission from the patient's parents.

Audio tape was used to record all the interviews to discover exact feeling, attitude and emotions of the participants during interviews. The interview was conducted in Bengali as though they can understand the questions easily. Face to face interview was conducted because this may provide higher response than other data collection methods. Every interview lasted for 15-20 minutes. Interview continued until saturation point was reached, that is no major new insights were being revealed and there was repetition of the same issues with different respondents. Data was collected in between 13<sup>th</sup> may-15<sup>th</sup> may, 2017. Each data was collected carefully and confidentially was maintained. Each participant provide particular time to collect data. Each questionnaire took approximately 10-15 minutes to complete.

### **3.11 Data Analysis**

The data analysis mainly involved the transcript of the interviews, identifying themes and then incorporating those themes into the next stage of data collection. Some questions were ask to the participants by preparing a semi structure questionnaire. The question were analyzed as the first step to data analysis. For a better analysis, the individual responses were read thoroughly for several times to identify the actual meanings and themes from the responses. Finally seven themes were listed and codes were developed from the list. According to the codes, the differences between each other were detected. The codes were also defined clearly with their actual meaning. For that reason, overtime the participant's perceptions were coded carefully according to their actual meaning and followed in each question. The next step is the content analysis of the topic. Here the researcher carefully divided the topic into same categories. Finally theme will be known from each category.



### **3.12 Ethical Consideration**

Researchers have ethical responsibility to recognize and protect the rights of human research participants. Human rights that require protection in research are the right to self-determination, right to privacy, right to anonymity and confidentiality, right to fair treatment and protection from discomfort and harm(The British psychological society,2010).This five principles of human rights also guided ethical consideration for this research. The ways of protective the five human rights were divided into three parts: before, during and after data collection. Before data collection, the research was approved by Review committee of BHPI. After obtaining approval, the research process was begun. For the participant, the researcher provide detailed information to protect the five human rights as described in the consent form .The information included: A detailed description of the purpose and procedure of the research, the benefits and the risk of joining the research. There were no expected risk for participants during the research period. The only inconvenience answering question during interviews and the researcher's presence in their living places. They had the right to decide the participants in this research, and they could with draw from this research at any time. If they decided not to participate, their decision would not impact on the quantity and quality of care for their family member from therapy team. The collected information was kept confidentially and only the researcher could access those data. The collected data would not be disclosed or identified with an individual's name. After data collection, all collected data was transcribed and entered into one computer and two back-up copies into portable hard drives. All of the printed documents or raw data were locked in a file box and only the researcher could access those data. Those data were deleted or shredded and discarded after the research was finished. The research proposal was submitted to the ethical committee that Institutional Review Board (IRB) and approval was obtained from the Board Bangladesh Medical Research Council (BMRC) and World Health Organization (WHO) guideline also were followed to conduct the study.

### **3.14 Rigor**

Researcher always tried not to influence the process by her own value and biases .No leading questions were asked or no important question is avoided. While conducting the study the author took help from her supervisor and follows her direction appropriately.

At each table interview findings were described with coding. Under the different categories parent's different opinion is different codes. The tick was given only for those columns where the mothers spoke about those issues. Here 'P' was used for participant and 1, 2, 3.... indicate participant's number.

#### **4.1 Participant's Socio-demographic information**

In this study among 14 participants the mean age was 26.87 ( $\pm 14.15$ ) years with age range 20-39 years. Among the cerebral palsy child's parents both father and mother were included in this study, 12 were mother and 2 were father. The educational level among the participants one participants had Primary education, 03 participants had completed Secondary education, 05 participants had completed Higher secondary education, 03 participants had Bachelor degree, 02 participants had M.Sc.degree. 10 mothers were housewives, 02 mothers were service holder, 2 fathers were service holder Code name was used for all of the participants.

**Table -1: Socio-demographic information of the participants**

<b>Socio-demographic Information</b>	<b>Number of the Participants (n)</b>
<b>Age</b>	
22-30	10
30-39	04
<b>Sex</b>	
Male	02
Female	12
<b>Education level</b>	
Primary	01
S.S.C	03
H.S.C	05
Bachelor degree	03
M.Sc. degree	02
<b>Occupation</b>	
House wife	10
Service holder	04

### Age

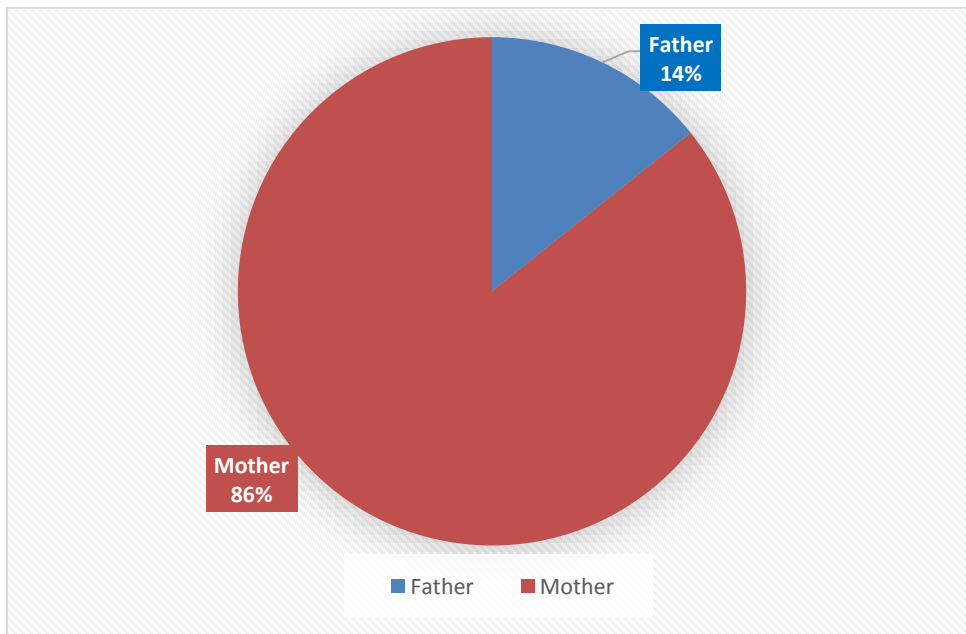
Among 14 participants 20-30 years old participants were 10 and (>30) years Old participants were 04.

**Table-2: Age distribution of parents**

	Total number	Minimum age	Maximum age	Mean
Age of the Participants	14	20	39	26.78

### Sex

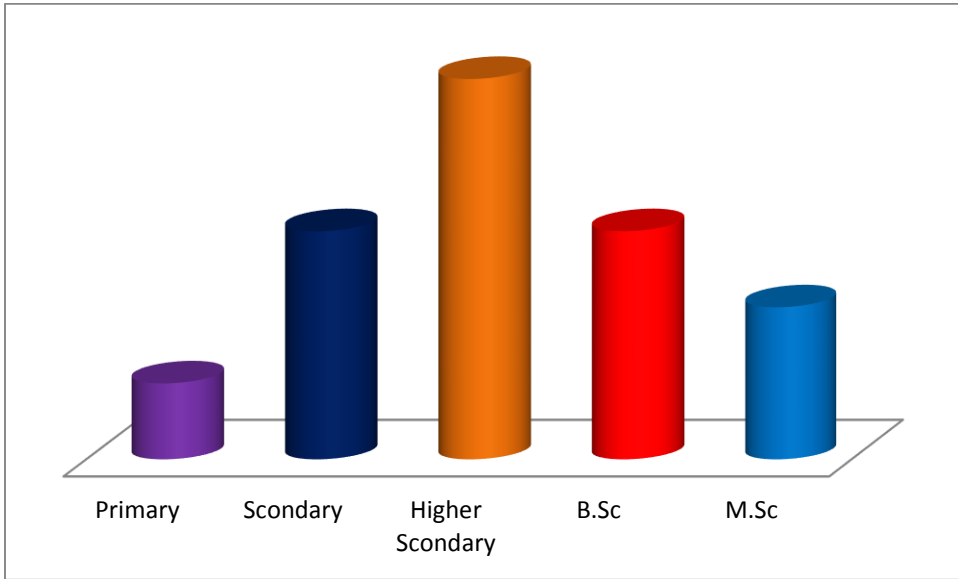
Among the participants, mother were 12 and father were 2.



**Figure 1: Sex distribution of parents**

**Educational status**

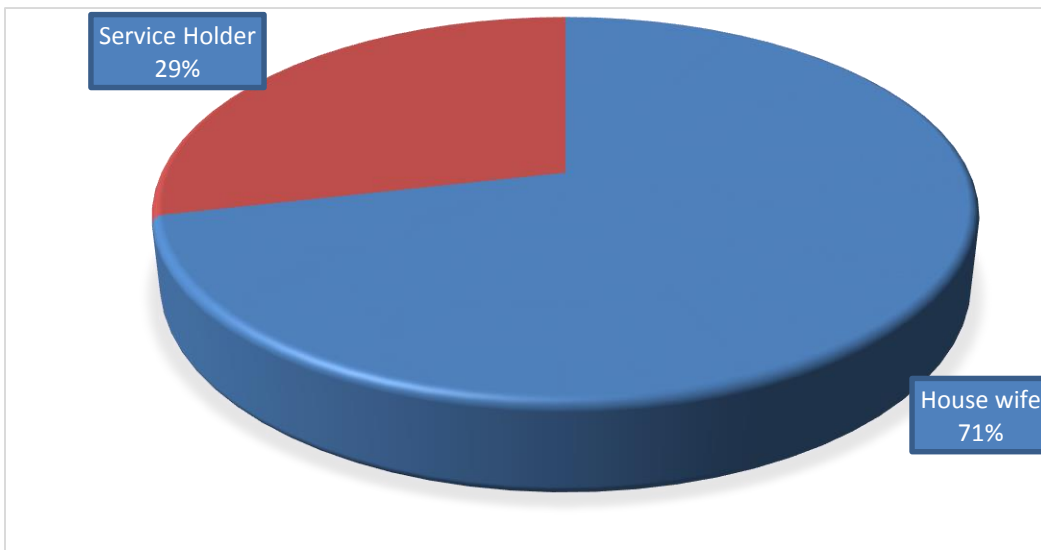
Among the 14 participants, 01 participants had primary education, 03 participants had completed secondary education, 05 participants had higher secondary education, 03 participants had Bachelor degree and 02 participants had M.Sc. degree.



**Figure 2: Educational Distribution of parents**

**Occupational status**

Among the 14 participants 10 mothers were housewife, 02 mothers service holder, 2 fathers were service holder.



**Figure 3: Occupation of parents**

### **4.3 Following Themes are emerged on the basis of data analysis**

**Theme-1:** Parents perceptions about the knowledge and condition of cerebral palsy.

**Theme-2:** Parents perception of the amount of time that parents can spend to perform their ADL's (self-care, productivity, leisure) along with taking care of their cerebral palsy child.

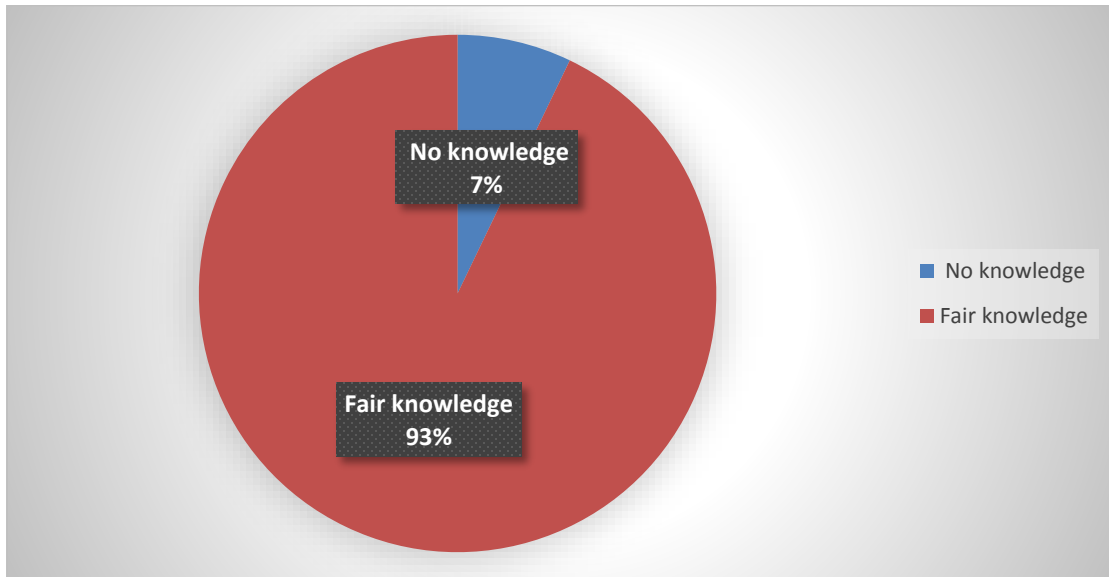
**Theme-3:** Perception of parents if they facing any challenges such a social, physical, psychological for a child with cerebral palsy.

**Theme-4:** For having a cerebral palsy child parents are facing different problems in their relationships.

**Theme-5:** For having a cerebral palsy child most of the parents faces economic problems because of spending money for treatment.

#### 4.3.1 Parent's knowledge about the condition of Cerebral palsy.

This theme relates to the parents knowledge about cerebral palsy. The participant's responses are displayed below.



**Figure 4: Knowledge regarding the cerebral palsy child's parents**

According to the transcript, 01 participant have no knowledge about the condition of cerebral palsy. 13 participants were only knew about cerebral palsy after their child was born. Before that they had no idea about cerebral palsy. Mothers said, “when my child had become cerebral palsy then I had known about cerebral palsy, before that I had never know about what is cerebral palsy”.



#### 4.3.2 Parent's ability to perform their ADL's properly.

**Table-3: Parent's ability to perform their ADL's properly:**

To find out the every participants was asked the same question. The participant's responses are displayed at below:

<b>Coding</b>	<b>Able</b>	<b>Not able</b>
<b>P1</b>	-	✓
<b>P2</b>	✓	-
<b>P3</b>	-	✓
<b>P4</b>	-	✓
<b>P5</b>	✓	-
<b>P6</b>	-	✓
<b>P7</b>	✓	-
<b>P8</b>	-	✓
<b>P9</b>	-	✓
<b>P10</b>	-	✓
<b>P11</b>	-	✓
<b>P12</b>	✓	-
<b>P13</b>	✓	-
<b>P14</b>	-	✓

In this table showed that, most of the parents (09) can't able to perform their ADL's properly. Only 5 parents able to perform their ADL's activity.

### 4.3.3 Parents experiences about physical, social and psychological challenges

**Table-4: Parents experiences about their physical challenges**

Here the researcher wanted to know the parents perception about their physical challenges.

The participants are displayed below:

<b>Coding</b>	<b>Impact on</b>	<b>No impact on</b>
<b>P1</b>	✓	-
<b>P2</b>	-	✓
<b>P3</b>	✓	-
<b>P4</b>	✓	-
<b>P5</b>	-	✓
<b>P6</b>	✓	-
<b>P7</b>	✓	-
<b>P8</b>	✓	-
<b>P9</b>	-	✓
<b>P10</b>	✓	-
<b>P11</b>	✓	-
<b>P12</b>	✓	-
<b>P13</b>	-	✓
<b>P14</b>	✓	-

All the participants shared their experiences of the physical challenges of the extra care-giving needs of their children. To explain about their physical challenges most participants admitted to tension, sickness, physical stress, high blood pressure, diabetes, sleep disturbances, headache, joint pain, feeling old in early age. Among 14 participants, 10 participants reported that they face some physical challenges, 04 participants stated that “they don’t face any physical challenges”.

**Table-5: Parents experiences about social challenges**

Parents are facing different social challenges like stigma and lack of support from neighbors on the other hand some of them oppose with this. The participant’s responses are displayed below:

<b>Codes</b>	<b>Experienced parents</b>	<b>Non-experienced parents</b>
Neighbors are not enough sympathetic towards child	P12	P1 P6 P11 P2 P7 P12 P3 P8 P13 P4 P9 P14 P5 P10
Experiencing stigma like blame mother for child’s condition	P2, P10, P5, P13, P6, P14. P7,	P1, P8, P3, P9, P5, P11, P6, P12.

Most of the participants mentioned that their neighbors are enough sympathetic towards them. One mother said, “Actually some of them sympathetic and some of them are lough or tease”. 08 participants of the study mentioned that they are experiencing stigma like blaming themselves for their child’s condition and so on. 06 participants of the study mentioned that they are not experiencing stigma due to having a child with cerebral palsy.

**Table-6: Parents experiences about their psychological challenges**

In this study, researcher wanted to find out that parents are always remain in frustration and grief to think about their children with cerebral palsy and this may lead negative psychological outcomes parents. The participant's responses are displayed below:

<b>Coding</b>	<b>Frustrated</b>	<b>Non-Frustrated</b>
<b>P1</b>	✓	-
<b>P2</b>	✓	-
<b>P3</b>	✓	-
<b>P4</b>	✓	-
<b>P5</b>	✓	-
<b>P6</b>	✓	-
<b>P7</b>	✓	-
<b>P8</b>	✓	-
<b>P9</b>	✓	-
<b>P10</b>	✓	-
<b>P11</b>	✓	-
<b>P12</b>	✓	-
<b>P13</b>	✓	-
<b>P14</b>	-	✓

Here showed, most of the participants always remain in frustration and grief for the child due to think about the future of the child after their death, society people's attitude towards the child is a common stressor for them and sometimes they feel guilt for their child's condition so they feel frustration. Only 01 participant was not frustrated with their cerebral palsy child.

#### 4.3.4 Parents perception about their relationships status with cerebral palsy child.

**Table-7: Problems in the relationship of parents**

Problems of parents in the relationship arise in many ways for having cerebral palsy child. Here researcher wanted to find out the parents perception about their relationship with cerebral palsy child. The participant's responses are displayed below:

<b>Parents ID No</b>	<b>Impact on</b>	<b>No impact on</b>
<b>P1</b>	✓	-
<b>P2</b>	-	✓
<b>P3</b>	✓	-
<b>P4</b>	-	✓
<b>P5</b>	✓	-
<b>P6</b>	-	✓
<b>P7</b>	✓	-
<b>P8</b>	-	✓
<b>P9</b>	✓	-
<b>P10</b>	-	✓
<b>P11</b>	✓	-
<b>P12</b>	✓	-
<b>P13</b>	✓	-
<b>P14</b>	-	✓

Here showed that most of the parents, 08 parents are facing many problems that's why created many problems in their relationship. Only 6 parents have no problem.

#### 4.3.5 Parents perception about their economic status with cerebral palsy child.

**Table -8: Parents perception about their economic status**

When a child was disabled a lot of money was spent behind the child and it created many kinds of problems among parents and their family. Participant's responses are given below:

Parents ID No	Impact on	No impact on
P1	✓	-
P2	-	✓
P3	✓	-
P4	✓	-
P5	-	✓
P6	✓	-
P7	-	✓
P8	✓	-
P9	-	✓
P10	✓	-
P11	-	✓
P12	✓	-
P13	✓	-
P14	-	✓

Here showed that 08 parents are spending extra money due to childcare and child treatment that's why created many problems in their family. Only 6 parents have no economical problem.

Discussion section is a very important part, where the researcher can add her explanations to the work. In this critical part of the research paper, the researchers start the process of explaining any links and correlate those with findings of the study. The findings and discussion have been presented together with the necessary literature support (Shuttleworth, 2009).

The aim of the study was to identify the perception of parents about their cerebral palsy child after confirming the diagnosis. A qualitative study design was used to conduct the design. Fourteen parents of cerebral palsy child's were recruited in this study. The samples were selected convenience sampling method. The data were collected by using a semi-structured questionnaire form and coded by five themes; finally the coded data are analyzed and presented qualitative analysis. Following themes have been emerged on the basis of data analysis. These include, Parents' understanding about the condition of Cerebral palsy, parent's ability to perform their ADL's properly, Parent's experiences about their physical and psychological challenges, Parents are facing different social challenges like stigma and lack of support from neighbors on the other hand some of them oppose with this, For having a cerebral palsy child most of the mother faces problems in their relationship with their in-laws which is mostly due to spending extra money in childcare.

Here, 14 parents both mother and father were included in this study. Among the participants, 12 participants were mother and 02 were father. 20-30 years old participants were 10 and (>30) year's old participants were 04. Among the participants, mother were 12 and father were 2.

Here, 01 participants had primary education, 03 participants had completed secondary education, 05 participants had higher secondary education, 03 participants had Bachelor degree, and 02 participants had Master's degree. And the study showed that maximum parents was not highly educated because of their poor financial condition. Parents' educational level were 7.7% primary level completed, 21% S.S.C completed, 35% H.S.C

completed, 21% bachelor and 14 % Masters. Another way father's educational level were completed 4.7% under primary, 27% primary, 13.7% J.S.C, 13% S.S.C, 11% H.S.C, 13% bachelor or above and 17.7% others. At the same time we saw another study in U.S.A mother's education was 6.7% H.S.C completed (Hwang et al., 2011). In Australia, one study found in mothers were completed 1.5% primary level, 37.2% high school level, 22.1% trade certification and 29% university. And father's education was 0.5% primary school, 39.2% high school, 29.4% trade certification, 23% university level completed (Davis et al., 2009). In Bangladesh, mother was not educated 38% found one study (Mobarak et al., 2000).

Among the parents 10 mothers were housewife, 02 mothers were service holder. Means most of the mothers were housewives which was 71% whereas only 14% were service holder. In other hand in America, working caregiver was 38% and not working caregiver 62% (Allah et al., 2012). Participant's parents had number of child 42 one 46%, two 31%, three 16.7% and more than three 6.3% in this study. In American journal showed a study that was one-two 32%, three-four 36%, more than five 32% number of children (Allah et al., 2012).

The study showed that 01 participants have no knowledge about the condition of cerebral palsy. 13 participants only knew about cerebral palsy after their child was born. Before that they had no idea about cerebral palsy. Mothers said, "when my child had become cerebral palsy then I had known about cerebral palsy, before that I had never know about what is cerebral palsy".

This study found that most of the participants have lack of knowledge about the condition of cerebral palsy and the general public has lack of knowledge about the disorder too. In published studies it is also found that mothers and society people generally has lacked awareness about this disorder. Parents of cerebral palsy child had many knowledge gaps regarding the illness of their children. Similarly low levels of knowledge and practices have been reported among the parents of cerebral palsy child with various chronic diseases (Rocker et al., 2012).



Based on their participants' opinion it's clear that most of mothers have not enough knowledge about the cause of their child's cerebral palsy. But some of them have little idea and a few of them has misconceptions about the cause of cerebral palsy.

In this study among 14 participants most of the participants are not getting adequate times to perform self-care activities. 5 participants are getting 1 -2 hours to perform those activities. Moreover very few of them are getting less time than those mothers. The mother said, "this is right I can't, but I try and after trying I get half an hour for myself".

Mothers persistently have to adjust between assembly the children's needs and having a typical life, but it is exceptionally troublesome to keep this adjust. Mothers moreover tend to donate small time for themselves due to care-giving requests of their children with cerebral paralysis (Ebrahimi et al., 2013).

In this study, it is found that mothers get less time to perform their own self-care activities, as the literature has indicated. This is due to continuous care-giving demands and mothers leave their own daily life needs, and become unconscious about their own self-care activities and how it impacts on their quality of life. Most of the participants are not able to perform their productive activities like house-hold activities and official activities properly, besides taking care of their child in home. Mothers said that, "I am not able to perform properly". A few participants said that "they are performing their house-hold activities quite well as well as taking care of their child, and very few participants said that they were doing their house-hold works besides take care of their child, but at the same time they feel very trouble".

Giving physical help for everyday living to children with disabilities can be exceptionally time expending for the parents. In a study of Taiwan, numerous guardians detailed that they had no time for themselves. Time was a major recreation limitation for them. Indeed when those guardians taken an interest in recreation exercises, they were persistently on edge around their child's condition. They detailed that they were not able to appreciate the recreation movement since they were not completely locked in in it. In this think about, as

well as in the writing, it is found that mothers are not getting sufficient time for their relaxation, and this causes stress (Hsieh & Puymbroek, 2013).

Among 14 participants 9 participants feel some physical problem for having care of their cerebral palsy child. Another 04 participants are giving lots of time with their child and giving special care for them, it has no impact on her physical condition.

All the participants shared their experiences of the physical challenges of the extra care-giving needs of their children. To explain about their physical challenges most participants admitted to tension, sickness, physical stress, high blood pressure, diabetes, sleep disturbances, headache, joint pain, feeling old in early age. That is much deviated result found from this study. All literature said that the mothers are facing lots of challenges in their physical aspects. Children who are less aggressive behaviors, their mothers feel more relief. For that sometimes they can manage their works and less impact on their physical condition (Barbera, 2007).

In this study, it is found that most of the parents are facing different physical problems due to care-giving burden like headache, sleep disturbance, high blood pressure, joint pain, sickness. Very few of them reported no experience of facing any physical problems. Based on Literatures, parents of child with cerebral palsy faced different physical problems due to high level of stress of care-giving.

Mothers of children with cerebral palsy have to faces some social suffering.

Among 14 participants 13 participants mentioned that “their neighbors are enough sympathetic towards them”. One of the mother said “actually some of them sympathetic and some of them are lough or tease”.

It was moreover supported by writing that the community individuals frequently recognized parents adversely and parents were stigmatized and faulted for having a child with disability (Yousafzai et al., 2011). When parents go outside of their house, such kind of negative attitude and negative talking hurt the mothers. So mothers try to avoid that

place and these persons. By this way mothers social interactions were decreased and they are lag behind from social activities.

Writing appeared that a few family individuals like parents-in-law of mothers of cerebral palsy child think that an impaired child can bring social shame and disgrace to their family. So they need to cover up their children from society (Huang et al., 2012). They don't want that the disabled child is familiar with other peoples and their mother go outside with her child.

In the literature it was found that mothers get little additional support from their husband and from extended number of the family for the care of child with disabilities and household activities. For this many mother were often confined to the home and restricted in social and community activities (Yousafzai et al., 2011)

Literature appeared that the destitute design of open facilities influenced the impaired child's association exterior of home. Mothers moreover felt frail and disappointed when their impaired child was the casualty of individual bias and had trouble to relate with their peers. For these whole reasons mother pull back themselves from advance social engagement (Huang et al., 2005).

Here, 08 participants of the study are experiencing stigma like blaming themselves for their child's condition and so on. 06 participants of the study are not experiencing stigma due to having a child with cerebral palsy.

Need of information around this disorder impacted the society individuals to fault mothers for their child's condition. They are accepted that mothers have abused a few social rules for that they get children with inability. In a consider in Bangladesh detailed that, particularly the matured one in family individuals faults the spouse to given birth of a child with disability (Rakib, 2013)

In this study, one of the participant mentioned that "society people are not enough sympathetic towards child with cerebral palsy and their parents" and most of the

participants mentioned that “society people are sympathetic towards them”. Moreover most of them are experiencing social stigma from society and mothers in-law for their child’s condition and some also contradict with this. Literatures also indicate that social support is very important for parents to cope with the adverse situation. So results can vary from society to society but most of the study indicated negative attitude is common from society toward disability. Parents of children with cerebral palsy always remain in depression and faced other psychological issues rather than parents of typically developing children.

Among 14 participants 13 participants are remain always in frustration and grief for the child due to think about the future of the child after their death, society people’s attitude towards the child is a common stressor for them and sometimes they feel guilt for their child’s condition so they feel frustration. Only 01 participants said that “they didn’t feel any type of stress or frustration”.

Parents experienced disturbed pain, outrage and disappointment when they know almost their cerebral palsy child and stress during the symptomatic revelation. These discoveries in the writing is knowing a guardians with a debilitated and chronically sick child got to be exceptionally stress full. (Dagenais et al., 2006)

It is well understood that parents of children with cerebral palsy are an expanded chance for encountering parental stress, on edge and depressive side effects. In reality, parents of children with formative disabilities, counting CP, encounter more prominent parental stress (Whittingham et al., 2013).

In this study, it is found that most of the parents are always remain in frustration and grief to think about their children with cerebral palsy and this may lead negative psychological outcomes for parents. Some of them provide self-blame on them for their child’s condition. This has an adverse effect on their mental health. But it is a matter of hope that most of the mothers don’t think them responsible for their child’s condition. Literatures reported that, self-blame, anxiety, depression, frustration are common in mothers of children with

cerebral palsy. But the situation is now changing, mothers become empowered and their concept becomes changing towards children with disabilities.

Here showed most of the participants are unable to give enough time and care to their other child due to providing extra care to the special child. They are facing many problems like they are unable to help their other children in study purpose, other children are getting less attention and care and they are often feel lonely and bored due to get less time and care. A special child requires high needs, which consume the parents time.

In this study, most of the mothers face difficulties to maintain care-giving balance between their children but some mothers can able to make balance between their children. But literature said that, maintaining the high needs of a child with autism most of the mother feels hesitate to fulfill the needs of other children thus negative psychological impact fall on siblings.

Problems of mothers in the relationship arise in many ways. When a child was disabled, a lot of money was spent behind the child and it created many kinds of problems among mothers.

Among 14 participants 08 participants of the parents said that for spending extra money due to childcare and child treatment there created many problems in their family.

Lot of money is went through by numerous families in looking for a remedy for their child disability. For a child with disability they require additional money. They require money for fundamental need of child such as nourishment and clothing and they require cash for clinic charge, assistive gadget etc. So it was an additional burden for a family and for this reason there made negative relationship among the family individuals. Superior quality conjugal connections impact superior quality parent-child connections. In the event that mother get spousal back at that point it gets to be exceptionally accommodating to manage with antagonistic circumstance (Hartley et al., 2005). A few studies detailed that there is a positive influence drop on the conjugal relationship since they have found appropriate ways to communicate and move forward physical and mental participation, after getting a special child. Conjugal struggle is more common in guardians of children with disabilities or maybe than parents with ordinary children (Bashir et al., 2014).

In this study most of the mother's opinion is there is no impact fall on their relationship with their husband. Researcher thinks that due to cultural perspective, most of the people of our country are restrictive and as the topic is so personal therefore they usually don't want to share their internal matter with the outsider. But some of them share their opinion with the researcher. Most of the participants said that their family members are sympathetic towards the child and themselves. Mothers said that, "yes sympathetic".

The attitudes of extended family members vary from family to family. Sometimes they seem like supportive, well-meaning but sometimes they seem like judgmental, negative and ignorant.

In this study, most of the parents reported that their family members are supportive and sympathetic towards them. But some of them oppose it. Usually family members attitude vary from house to house. It also depends on the knowledge of the family members about disability. In literature the evidence said that some study indicates family members are supportive and some study indicates negative attitudes are common from family members. Finally, researcher thought that after having a child with cerebral palsy parent's quality of life is hampered. They can't balance time with their own ADL's and also their other family members specially spouse and other children due to high care-giving demands of the special child. It also impacts their physical and psychological aspects. Moreover, lack of society and family support is also responsible for their increasing burden. It's mainly due to lack of knowledge about this disorder among society people, they usually show stigmatic attitude towards children with cerebral palsy and their parents. Mothers have lack of awareness too about this disorder therefore sometimes they feel guilt and self-blame on themselves for their child's condition.

Overall 14 parents' daily life and quality of life is decline after having a child with cerebral palsy and they faced different challenges physical, psychological, social and family aspects.

The aim of the study was to assess perceptions of parents having CP child. The result which found from the study has fulfilled the aim of this research project. Should take more sample for generating the result and try to make more valid and reliable. Outcome or result can be measured in a valid scale in further studies. Sample should collect from many institutes in Bangladesh. Should take more times for generating this research appropriately. This is an undergraduate study and doing the same study at graduate level will give more accurate output. There was some limitation of the study mentioned at relevant section. It is recommended to overcome those limitations during further study.

### 6.1 Conclusion

Cerebral palsy is a neurological disorder. In Bangladeshi perspective, parents especially mother have to maintain major care-giving responsibilities of their children and also have to manage their household responsibilities. As caring a child with cerebral palsy is very challenging therefore parents have to remain in ongoing stress. It often impacts their daily life and overall quality of life.

This study would be helpful to identify specific problems area and challenges of parents to provide appropriate emotional support and education to increase their self-esteem coping skills. From the result of the study, it has found that parents have lack of understanding about the condition. They usually don't get enough time to perform their ADL's properly due to high care-giving burden. Moreover, they also faced different physical, psychological, family and social problems after having a cerebral palsy child and thus their daily life and quality of life is decline greatly. It is also true that some parents take their child's related works positively and reported that they don't facing any problems and also it is a matter of hope that most of them don't blame themselves for their child's cerebral palsy as well as they are getting support from society and it is very helpful to reduce negative psychological outcomes of them.

This study is important for Physiotherapists as they can work with parents to increase awareness about cerebral palsy among mothers and society people, they can give motivation and education to the parents to increase their mental stability and coping skills. They also can run home visit and arrange open discussion with society people to reduce their stigmatic attitude towards cerebral palsy child. Schools those are working with cerebral palsy child may arrange parents or only mothers' session, self-help group session, sharing session to raise awareness and empowerment of mother and physiotherapist can organize those sessions. Government should come forward to help in organizing awareness raising and promotional program about cerebral palsy and its intervention to increase awareness in community people about cerebral palsy and its treatment.



## **6.2 Recommendation**

After completing the research the researcher found some recommendation. The researcher took small number of participants for the study and find out some perception of cerebral palsy child's parents. Then researcher felt that if she took large numbers of participants, she can get more information and can generalize the data. So further studied should be conducted with large number of participants including with different age and different educational level of parents. Further studies are also needed to find out parents perception of cerebral palsy child in Bangladesh. From the study finding researcher found that parents have many problems in their life for their child so parents came to receive treatment to improve their child condition and take it as a way to minimize their problems so therapist should take it in their mind and they should provide suggestion to the parents about their problems during intervention session.

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## APPENDIX

### VERBAL CONSENT FORM

(Please read out to the participant)

Assalamualaikum, my name is Fatematuj-Johora, I am conducting a study for partial fulfillment of Bachelor of Science in Physiotherapy degree, titled on

#### **“PARENTS PERCEPTION OF CEREBRAL PALSY CHILD AFTER CONFIRMING THE DIAGNOSIS”**

From Bangladesh Health Professions Institute (BHPI) under medicine faculty of University of Dhaka. I would like to know some information related to my study. This will take approximately 10-15 minutes. I need to meet you just once to collect entire information.

I would like to inform you that this is a purely academic study and information obtained will not be used for any other purpose. All information provided by you will be kept confidential and also the source of information will remain anonymous.

Your participation in this study is voluntary and you also have the right not to answer a particular question that you don't like or do not want to answer during the interview.

Do you have any questions before I start?

So may I have your consent to proceed with the interview?

Yes

No

Signature of the witness.....

Date.....

Signature of the participants.....

Date.....

Signature of the researchers.....

Date.....

## অনুমোদন পত্র

আমি ফাতেমা তুজ-জোহরা, 'বাংলাদেশ হেলথ প্রফেশনস ইন্সটিটিউট' এর চতুর্থ বর্ষের একজন ছাত্রী। আমি একটি গবেষণা করছি যার শিরোনাম হল “পেরেন্টস পারসেপশন অফ সেরেব্রাল প্যালসি চিল্ড্রেন” অথবা “পক্ষাঘাতগ্রস্ত শিশুর বাবা- মায়ের ধারণা” যেটা আমার অধ্যয়নের অন্তর্গত। এই জন্য আমি আপনার কাছে কিছু প্রশ্নের উত্তর জানতে চাচ্ছি যেটাতে সর্বমোট ১০- ১৫ মিনিট সময় লাগবে। এটাও নিশ্চিত করছি যে, আপনি যেসব তথ্য প্রদান করবেন তার গোপনীয়তা বজায় থাকবে।

এখানে অংশগ্রহন আপনার নিজের উপর নির্ভর করবে। আপনি চাইলে যে কোন সময় কোন ফলাফল ছাড়াই চলে যেতে পারেন। এ ছাড়াও যদি আপনার এই গবেষণায় অংশগ্রহনকারী হিসেবে কোন প্রশ্ন থাকে তাহলে আপনি আমাকে অথবা ফারজানা শারমিন, সিনিয়র ক্লিনিক্যাল ফিজিওথেরাপিস্ট, সিআরপি, সাভার, ঢাকা এর সাথে যোগাযোগ করতে পারেন।

গবেষণাটি শুরু করার আগে আপনার কোন প্রশ্ন আছে?

আমি কি আপনার অনুমতি পেয়ে এই সাক্ষাতকার টি আরাঙ্ক করতে পারি?

হ্যাঁ.....

না .....

সাক্ষাৎকার প্রদানকারীর স্বাক্ষর.....

গবেষকের স্বাক্ষর.....

সাক্ষীর স্বাক্ষর.....

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

## Questionnaires (English)

**Title: Parents perception of cerebral palsy child after confirming the diagnosis.**

### **Child's information:**

Child's age:

Sex:

Child's problem:

Child's birth position in the family:

Is he/she goes to school:

### **Parent's information:**

Age:

Level of education:

Occupation:

Religion:

How you pass your everyday life: (1) Good (2) very good (3) medium (4) bad (5) very bad

### **Household information:**

Who take care of the child in home?

Number of children in home:

Monthly income in the family:

### **Work related information:**

- (1) When and how did you understand your child's developmental problems?
- (2) What was your initial reaction after hearing about your child's cerebral palsy?
- (3) Many people have different opinion about cerebral palsy. Please explain your understanding about cerebral palsy?
- (4) What do you think about the reason behind your child's cerebral palsy?

(5) Are you able to perform your house-hold/official activities properly with taking care of your child in the home?

- How much time you can give to perform those activities please explain?

-Do you think it is enough for you if not then why not?

### **Physical**

(6)What do you think about your child physical health?

(7)You have to spend lots of time and have to give special care to your child. By maintaining this entire things how you feel physically?

-If not good then please explain the problems you are facing physically?

### **Family**

(8) Do you face any extra stress or impact on your family relationship due to your child?

-If you face problem then please explain the reason behind it and the problems you are facing because of it?

(9) Do you think that your other family members are supportive and sympathetic towards your autistic child?

-If not then please explain the reason behind it and the problems you are facing because of it?

### **Social**

(10) Do you think that your neighbors are supportive and sympathetic towards your child?

-If not then please explain the reason behind it and the problems you are facing because of it?

(11) Have you face any stigma due to having a child with cerebral palsy?

-If you faced then by whom and what kinds of stigma do you faced, please explain it?

### **Psychological**

(12) Do you think that you are only responsible for your child's cerebral palsy?

-If you think then why you think that please explain it?

(13) Do you feel frustration because of having a child with cerebral palsy?

-If you feel then please explain the reason behind it?

**Economical**

(14)Do you face any economical problem due to the cost of the child's treatment?

-If you face then please explain what type of problem?

## Questionnaires (Translated)

### প্রশ্নপত্র

#### বাচ্চা সম্পর্কিত তথ্যঃ

বাচ্চার বয়স-

লিঙ্গ-

বাচ্চার কি কি সমস্যা হয় -

আপনার বাচ্চা কি স্কুলে যায়-

#### বাচ্চার বাবা - মা সম্পর্কিত তথ্যঃ

বয়স-

শিক্ষাগত যোগ্যতা-

পেশা-

ধর্ম-

আপনার দৈনন্দিন জীবন কীভাবে কাটে- (১) খুব ভাল (২) ভাল (৩) মোটামুটি (৪) খারাপ

(৫) খুব খারাপ

#### পারিবারিক তথ্যাবলীঃ

বাসায় কে আপনার বাচ্চাকে দেখাশুনা করে-

বাসায় বাচ্চার সংখ্যা কতজন-

পরিবারের মাসিক আয়-

#### কাজ বিষয়ক তথ্যঃ

১) কখন এবং কিভাবে আপনি আপনার বাচ্চার বর্ধনজনিত সমস্যা বুঝতে পারলেন?

২) আপনার শিশুটি সেরিব্রালপালসি শিশু জানার পর আপনার মনোভাব কেমন হয়েছিল?

৩) অনেকের সেরিব্রালপালসিসমন্ধে বিভিন্ন ধারণা আছে। আপনার ধারণা কি?

৪) আপনার শিশুটির সেরিব্রালপালসিহওয়ার পেছনে কি কারণ আছে বলে আপনি মনে করেন ?

৫) ক. আপনার বাচ্চার যত্ন নেওয়ার পাশাপাশি আপনি কি আপনার গৃহস্থালি/অফিসের কাজগুলো সঠিকভাবে করতে

পারছেন?

খ. এই কাজগুলো করার জন্য কতক্ষণ সময় দিতে পারছেন দয়া করে বিস্তারিত বলুন?

গ. আপনি কি সময়টা যথেষ্ট মনে করেন, না হলে কেন যথেষ্ট নয় ?



### শারীরিক

৬) ক. আপনার শিশুটির বিশেষ যত্ন ও নিতে হয়, এসব কাজ করতে গিয়ে আপনার বর্তমান শারীরিক অবস্থার কোন পরিবর্তন হচ্ছে ?

খ. যদি ভাল না হয় তাহলে কি ধরনের সমস্যা অনুভব করছেন?

### পারিবারিক

৭) ক. শিশুটির জন্য আপনার সাথে আপনার পরিবারের সম্পর্কের উপর কোন প্রভাব পড়েছে কি?

খ. যদি সমস্যা হয় তাহলে কেন হচ্ছে এবং কি ধরনের সমস্যা হচ্ছে বলে আপনি মনে করেন?

৮) ক. আপনার পরিবারের অন্যান্য সদস্যরা শিশুটির প্রতি কি সহানুভূতিশীল বা তাদের কাছ থেকে কি আপনি সহযোগীতা পাচ্ছেন?

খ. যদি সহানুভূতিশীল বা সহযোগী না হয় তাহলে এর পেছনে কি কারণ আছে এবং কি ধরনের সমস্যা অনুভব করছেন বলে মনে করেন?

### সামাজিক

৯) ক. আপনার প্রতিবেশিরা আপনার এবং আপনার শিশুটির প্রতি কেমন মনোভাব প্রকাশ করেন, তারা কি সহানুভূতিশীল?

খ. যদি না হয় তাহলে এর পেছনে কি কারণ আছে এবং কি ধরনের সমস্যা অনুভব করছেন বলে মনে করেন?

১০) ক. আপনার বাচ্চাটি সেরিব্রালপালসি হওয়ার ফলে আপনি কোন ধরনের অপবাদের স্বীকার হচ্ছেন কি?

খ. যদি হয়ে থাকেন তবে কাদের দ্বারা হচ্ছেন এবং কি ধরনের অপবাদের স্বীকার হচ্ছেন বলে মনে করেন?

### মানসিক

১১) ক. আপনার বাচ্চার সেরিব্রালপালসি হওয়ার জন্য আপনি নিজেকে কি দায়ী মনে করেন?

খ. যদি মনে করেন তাহলে কেন মনে করেন দয়া করে বিস্তারিত বলুন?

১২) ক. আপনার বাচ্চাটি সেরিব্রালপালসি হওয়ার ফলে আপনি কি হতাশা অনুভব করেন?

খ. যদি করেন তাহলে কেন হতাশা অনুভব করেন?

১৩) ক. আপনি কি মনে করেন একটি সেরিব্রালপালসি শিশু হওয়ার ফলে বাবা-মায়ের জীবনে বিরূপ প্রভাব ফেলে?

খ. যদি মনে করেন তাহলে কেন মনে করেন

### অর্থনৈতিক

১৪) ক. আপনার বাচ্চার চিকিত্সার খরচের কারণে আপনার অর্থনৈতিক কোন সমস্যা হচ্ছে কি?

খ. যদি হয় তাহলে কি রকম সমস্যা হচ্ছে বলে মনে করছেন?

**Permission Letter**

26<sup>th</sup> April, 2017

The Head

Department of Physiotherapy

Center for the Rehabilitation of the Paralysed (CRP)

CRP, Chapain, Savar, Dhaka-1343.

**Through:** Head, Department of Physiotherapy, BHPI.

**Subject:** Application for permission for data collection.

Dear Sir,

With due respect and humble submission to state that I am Fatematuj - Johora, student of 4<sup>th</sup> Professional B.Sc. in Physiotherapy at Bangladesh Health Professions Institute (BHPI). The ethical board of BHPI has approved my research project entitled on "Parent's perception of Cerebral Palsy child after confirming the diagnosis". To conduct this research, I want to collect data from the children with cerebral palsy who are admitted in Pediatrics unit at CRP. So, I need your permission for data collection from the children with cerebral palsy from pediatrics unit at CRP. I would like to assure that anything of my study will not be harmful for the participants.

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

Sincerely  
Fatematuj-Johora,  
Fatematuj -Johora

4<sup>th</sup> Professional B.Sc. in Physiotherapy  
Class Roll-22, Session: 2012-2013  
Bangladesh Health Professions Institute (BHPI)  
(An academic Institute of CRP)  
CRP, Chapain, Savar, Dhaka-1343.

Approved  
Please contact with Shaharuj  
Sultan, Senior PT @ Incharge  
Paeds. Physiotherapy Service.  
As a component of his data  
collection process.

Mohammad Anwar Hossain  
Head of Physiotherapy Dept.  
CRP, Chapain, Savar, Dhaka-1343

Recommended & Forwarded  
7/26/17  
Md. Obaidul Karim  
Associate Professor & Head of the Department  
Department of Physiotherapy  
Bangladesh Health Professions Institute (BHPI)  
CRP, Chapain, Savar, Dhaka-1343  
Tajjuna Shorruin  
Sr. PPT and Lectures BHPI  
26/04/17



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

Ref: CRP-BHPI/IRB/04/17/112

Date: 15/04/2017

To  
Fatematuj- johora  
B.Sc. in physiotherapy  
Session: 2012-2013, Student ID 112120023  
BHPI, CRP, Savar, Dhaka-1343, Bangladesh

**Subject: "Parents perception of cerebral palsy child after confirming the diagnosis".**

Dear Fatematuj-johora,

The Institutional Review Board (IRB) of BHPI has reviewed and discussed your application on 16/08/2017 to conduct the above mentioned thesis, with yourself, as the Principal investigator. The following documents have been reviewed and approved:

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

Since the study involves a self-administered questionnaire that takes 20 to 30 minutes and have no likelihood of any harm to the participants. The members of the Ethics committee have approved the study to be conducted in the presented form at the meeting held at 09:00 AM on August 17, 2016 at BHPI.

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

Best regards,

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

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

