

# **QUALITY OF LIFE OF MOTHERS OF CHILDREN WITH CEREBRAL PALSY**

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

## **QUALITY OF LIFE OF MOTHERS OF CHILDREN WITH CEREBRAL PALSY**

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## **Declaration**

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

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## Acronyms

<b>BHPI</b>	:	Bangladesh Health Professions Institute
<b>CP</b>	:	Cerebral Palsy
<b>CRP</b>	:	Centre for the Rehabilitation of the Paralysed
<b>GMFCS</b>	:	Gross Motor Functional Classification System
<b>IRB</b>	:	Institutional Review Board
<b>HRQoL</b>	:	Health Related Quality of Life
<b>SPSS</b>	:	Statistical Package for the Social Science
<b>WHO</b>	:	World Health Organization

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## Abstract

Cerebral palsy is one of the most common congenital disorders of childhood. That affects muscle tone, movement, and motor skills. And that's why they are dependent on their family, and the family especially the mother take the responsibilities to take care of the children with lot of stresses. And this condition decrease the quality of life of mother.

**Purpose:** Identify the quality of life of mothers of children with cerebral palsy. **Objectives:**

To identify the lifestyle of mothers of children with cerebral palsy. **Methodology:** Here use the cross sectional study method with 120 participants of mothers with their CP children. In additionally identify the quality of life of mothers of children with cerebral palsy.

**Results:** Data was analysed by using SPSS version 20. Microsoft Excel Work 2013. A total 120 participant of mothers with cerebral palsy children. Here minimum age of the mothers was 14 years and maximum age was 37 years. Among that the mean age of the mothers was 21.40 years and SD was 4.410. Among 120 participant mothers, most of them (40.80%) was completed secondary education level. All the 120 participants, 19.20% (n=23) got marriage with their cousin and 80.80% (n=97) was not. Among 120 participants, 9.20% (n=11) had more than one disable children and 90.80% (n=109) were not. Quality of life of mothers was detected by a questionnaire SF36 and there was 8 dimensions, from these dimensions the mean score of physical functioning was 51.21%, Role limitation due to physical health was 64.27%, Role limitation due to emotional problem was 62.15%, Energy or fatigue was 47.55%, Emotional well-being was 55.29%, Social functioning was 92.60%, Pain was 87.54%, and lastly general health was 46.29%. And functional level of children was detected by GMFCS score and maximum children was at level II(44%) and minimum was at level V(13%). The results was actually based on SF36 score of mothers & GMFCS level of the children. Here mainly access the quality of life of mothers. **Conclusion:** It was true that QoL of mothers was not very good with CP children, but there was no relation between functional limitations of CP children with their mothers QoL. Therefore, to increase QoL of mothers should be motivated them to join social activities related to their interests, and also care their own health. Mothers with depressive symptoms should be psychologically supported.

**Keywords:** Cerebral Palsy, Quality of life of mother, SF36, GMFCS.

## 1.1 Background

Cerebral palsy (CP) is a syndrome that encompasses a large group of childhood movement and posture disorders. It also involve motor impairment and associated impairments such as those of communication, intellectual ability, and epilepsy. Its severity and patterns of damage spread vary widely (Colver et al., 2014). During a baby's development in the womb, cerebral palsy results from brain injury and this is call congenital cerebral palsy. Although it is present from birth it may not be detected for months and 70% of children of cerebral palsy is responsible for about birth defect (WebMD, 2013).

There “the cerebral palsies” would be better named of CP .That given within the CP clinical spectrum there are many causes and many types of CP and various degrees of disability. These various pathways and etiologies have each resulted in a nonspecific and non-progressive disorder of posture and movement control. Thus, CP should be considered as a broad term for affected individuals, with each case get adequate consideration of an underlying causes (MacLennan et al., 2015). It is now found that assessing the extent of activity restriction is a part of CP evaluation and that’s why people without activity restriction should not be included in the CP term (Rosenbaum et al., 2007). In studied of CP there are historically been a relation to the pathology and etiology of the impairments of the CP. Although participation is an important construct and valued goal, and how it is conceptualized, defined and measured varies widely (Hammel et al., 2008). In developed countries, International assessments propose that CP affects between 1.2 and 3.0 per 1000 children (Hustad et al., 2010). The incidence of CP is considered to be 2 to 2.5 per 1000 live births and in the developing countries the prevalence of CP tends to be in a similar range (Bialik et al., 2009). CP occurring in approximately 2 to 2.5 per 1000 live births and the main problem of CP is physical disability .There has been growing interest in the quality of life of children with CP in recent years (Davis et al., 2010). Another study showed that the prevalence of cerebral palsy is 1.2 - 2.5 per 1000 live births although, the rates vary from country to country and also within the countries (Wolraich et al., 2008). In Southern Sweden there were 358 CP children, corresponding to a prevalence of 2.70 per 1000 live births. Of these children, 136 (38%) were classified as GMFCS level III - V. In the

Norwegian counties there were 494 children with CP born between 1st January 1996 and 31st December 2003, corresponding to a prevalence of 2.65 per 1000 live births (Elkamil et al., 2011). A systematic review, published in 2008, examined the prevalence of CP only in relation to gestational age and demonstrated a significant decrease in the prevalence of CP with increasing gestational age (Himpens et al., 2008). There are a median prevalence of 11.2 per 1000 live births for preterm infants, was reported among children weighing between 1500g and 2499g at birth, and 63.5 per 1000 live births among children weighing less than 1500g. There are a review that did not follow the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-analyses) statement and had various several methodological limitations (Oskoui et al., 2013). Often, parents feel alone in the fight against the disease, they had lack of support of this system. To ensure proper care for their loved one, one parent usually resigns from work. Cerebral palsy is a group of symptoms associated with etiologically varied central nervous system damage. Children with CP may also experience a wide range of social and emotional problems, such as rejection by friends, depression, frustration, anxiety, and anger. In addition, treatment and care of children with CP can be burdensome to parents in terms of cost, time and stress and that leading to the risk of unstable family conditions and low ability to cope with problems. Therefore, the quality of life of children with CP is one of the important assessments in evaluating the effectiveness of treatment of CP (Viehweger et al, 2010). Hilari et al. (2016) suggested on research that- World Health Organization (WHO) defines the QoL with more narrowly focused on health-related QoL and also follows as 'the individual's perception of their position in life in the context of their culture and value systems in which they live, and in relation to their goals, expectations, standards, and concerns. Quality of life (QoL) has been described as an individual's perception of his/her own status in life as to cultural features and value system. Health-related quality of life (HRQoL), however, is a subcomponent of QoL including physical, social, and emotional status of wellbeing. HRQoL is the happiness and satisfaction of individuals in different parts of life influencing or influenced by individuals' health (Dayapoglu & Tan, 2010). Dale et al. (2006) find out when a child has a disability, most families experience some distress. Parents may experience, emotional stress, anxiety, fear, and guilt. They may have to rearrange their way of life to accommodate their child, and the child's problems such as generalized motor disabilities,

absence of language, and behavioural difficulties are likely to exacerbate stress levels. The significant difficulties associated with cerebral palsy (CP) often necessitate that parents or primary caregivers gain additional skills and knowledge. They may also incur additional expenses that go beyond what is usual in raising a child. Bourke-Taylor et al. (2012) many mothers of children with developmental disabilities are known to experience high levels of stress, and compromised mental health and ultimately better service families raising and supporting a child with a disability. Quality of life of mothers in children with CP is a complex construct that is influenced by many factors. Chronic disorders of movement and posture in children with CP will cause a decrease in functioning and inability to perform activities of daily living (Sauve et al., 2010). Keller et al. (2009) showed that the routine and social activity of mothers was reduced due to disabilities of children that have an impact on disruption of activity of mothers. Kaya et al. (2010) suggested deterioration of mental health in mothers of CP causing them to experience more back pain which cause deterioration of health related Quality of life. All these suggest possible presence of Depression and affected Quality of life of mothers. But these results cannot be generalized to our population because different population has different characteristic. Diwan et al. (2011) found that children with cerebral palsy suffer from several problems like impaired gross motor function, and dysfunction balance, locomotion, sensory integration. So the family especially the mothers undertake a lot of stresses & social and emotional difficulties, 70% of mothers of children with CP suffering from mild to moderate level of depression and have affected Quality of life. Diwan et al. (2011) suggested that mothers with disabled children have anxiety & depression which affects mothers QoL. Sajed et al. (2010) had studied on 120 mothers of cerebral palsy children and found higher prevalence and severe depression. He had also found there is no difference in between depression score and severity of disability by statistically. Prudente et al. (2010) in his study showed the relation between QoL of mothers of children with CP and children motor functioning after 10 month of rehabilitation. Here suggested to know the relationship between SF-36 for QoL of mother with improvement in children gross motor level that was measured by GMFCS. But no relationship was found there. One of the influential conceptualization -of Lawton who described it as ‘the multidimensional evaluation, of quality of life by both intrapersonal and social-normative criteria, of the person–environment system of an

individual in time past, current and anticipated. In a recent study from Sweden, men and women of more than 67 years old were asked what quality of life was for them, and the responses of these persons were social relations, health, activities, functional ability, well-being, living in one's own home, personal finances, and personal beliefs and attitudes. (Netuveli & Blane, 2008). Arnaud et al. (2011) stress in their report that, although care is a normal part of being a parent of a young child, this role has a complete different meaning when the child has functional limitations and possible long-term dependence. One of the main challenges for parents is to solve chronic health problems associated with disability and to effectively meet the demands of day-to-day life. Therefore, the task of caring for a disabled child at home can be difficult for the parents. Providing such care can have adverse effects on both the physical and mental health of the parents, which we have also found in our research. A study by Garel et al. (2007) revealed the main problems for giving birth a premature baby whose were fatigue, depressed mood, anxiety and physical inability symptoms of the mothers. There are several factor that are associated with depressed mood those were social isolation, post-traumatic symptoms, withdrawal and feelings of guilt. It is worth noting that Edwards et al. (2011) emphasizes that QoL of mothers could not be separated from many other aspects of their overall health, if the child was not more relaxed, calmer and less anxious.

## **1.2 Rationale**

Many studies have done about perception, risk factor, burden, physical and psychological stress, depression, efficacy of PNF stretching program with cerebral palsy. But there is lack of researches about the quality of life of mothers of cerebral palsy children in our country. This research is about that. People with cerebral palsy has long term disability and mothers are the primary care giver of them. Previous studies show that quality of life of mothers of CP children significantly lower in compare to mothers of normal children. Gross motor function is an important tool to assess the ability of CP children and higher gross motor function denotes higher the functional ability. Quality of life of mothers of CP children can be related with many factors but it is still inconclusive that the gross motor function has any influence on quality of life of mothers. This study was aim to clarify this issue further. I also tried to find out the difference between foreign country and our country, because there is no enough research about this matter in our country.

Environmental factors not only affect people's social cooperation, but also their quality of life and this is far more important in mentally disabled people than the general population (Glanz et al., 2010). "Quality of life of mothers" for these families depend on children chronic conditions and also economic, social, and community support conditions. Children characteristics, parents' personalities, like family size, education level, occupation, income, and housing type and their coping strategies not on levels of impairment of the child (Mugno et al., 2007).

### **1.3 Research question**

What is the quality of life of mothers of children with cerebral palsy?



## **1.4 Aim of the study**

To find out the quality of life of mothers in relation to Gross motor function of their children.

## **1.5 Objectives**

### **1.5.1 General objective**

To identify the quality of life of mother of children with cerebral palsy in general. How they work with the children and how they manage their life.

### **1.5.2 Specific objectives:**

1. To identify the socio demographic characteristics including age, sex, educational level, area of living, occupation, sibling.
2. To identify health- related quality of life (HRQoL) of mothers with cerebral Palsy Children by using SF36.
3. To find out gross motor function level of CP children by using Gross Motor Functional Classification System (GMFCS).
4. To identify the relationship between Health-related quality of life (HRQoL) of mothers and gross motor function of their children.

## **1.6 Operational Definitions:**

### **Cerebral palsy**

Cerebral palsy (CP) is the term used for a group of non- progressive disorders of movement and posture caused by abnormal development of, or damage to, motor control centers of the brain. CP is caused by events before, during, or after birth. The abnormalities of muscle control that define CP are often accompanied by other neurological and physical abnormalities.

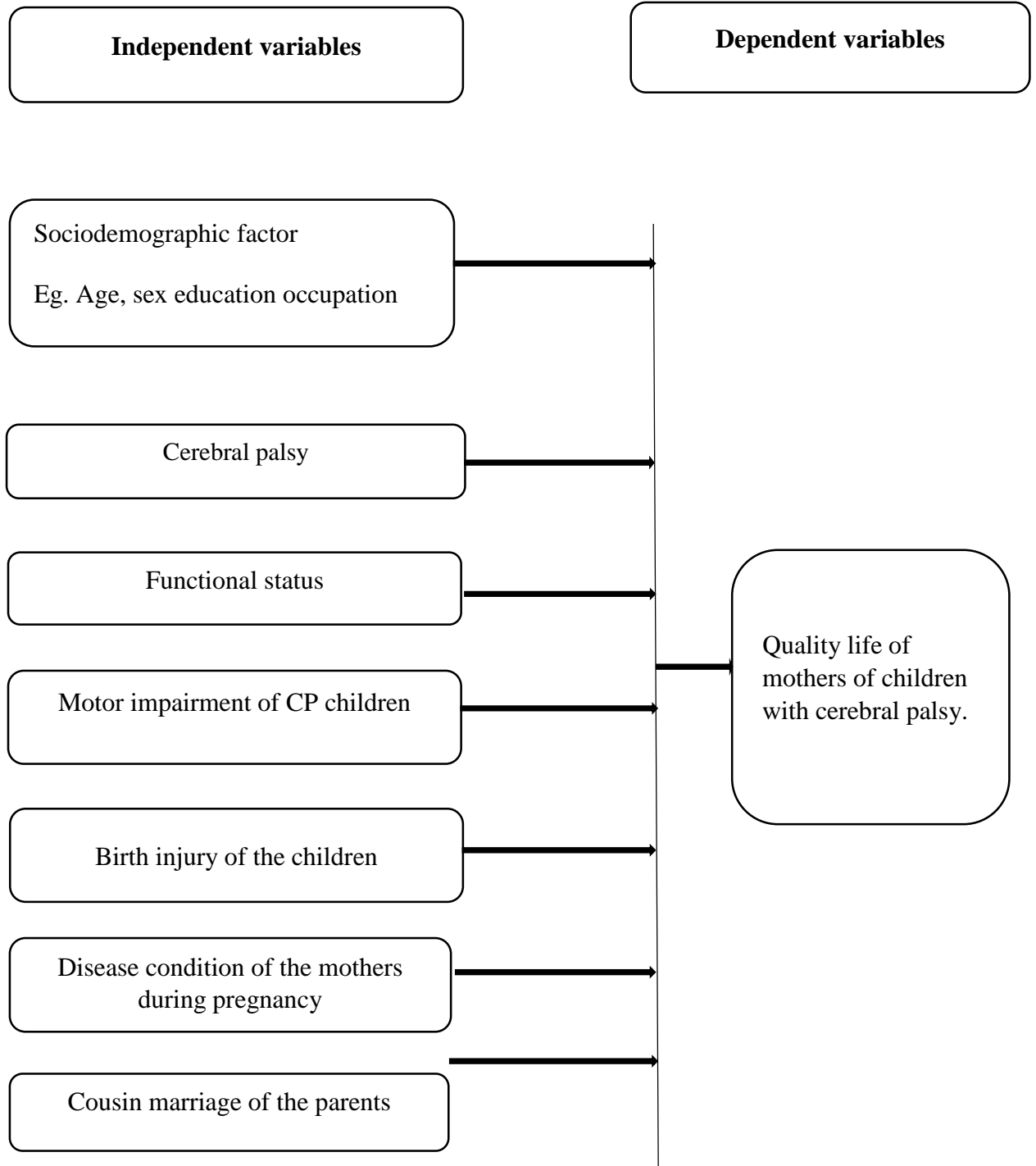
### **Health-related quality of life**

The general well-being of a person or society, defined in terms of health and happiness, rather than wealth. Health-related quality of life (HRQOL) is a multi-dimensional concept that includes domains related to physical, mental, emotional, and social functioning. It goes beyond direct measures of population health, life expectancy, and causes of death, and focuses on the impact health status has on quality of life. The measurement of health-related quality of life and well-being from a multidisciplinary perspective that encompasses 3 complementary and related domains are- Self-rated physical and mental health, Overall well-being, Participation in society.

### **Functional impairment**

Any loss or abnormality of physiological, psychological, or anatomical structure or function, whether permanent or temporary. Identifying impairments that contribute to disability, a functional problem for a patient.

## 1.7 Conceptual Framework



## 2.1 Literature Review

Rosenbaum et al. (2007) state that the Cerebral palsy can be described by its motor type and body parts distribution (topography). Now cerebral palsy (CP) is familiar to most of the professionals such as, health and social service as well as to many members of the general public, it is a physically disabling condition. This condition is clinically divided into four types; Spastic (atypical stiffness and rigidity in limb musculature), Athetoid (unintentional body movements), Ataxic CP child is characterized by problems in motor incoordination and Mixed type which is combination of Spastic and Athetoid (Mughal et al., 2012). The GMFCS levels range from Level I to Level V, and focus on gross motor function. The GMFCS level was used in order to classify the functional level of the children with CP. A generic health-related quality of life (HRQOL) questionnaire has recently been adapted for children with CP (Waters et al., 2010).

Mentally retarded children mothers may or may not have a negative effect on social adjustment. There is a difference between social adjustment in mothers of mentally retarded children and mothers of normal children (Koohsali et al., 2008). Tan et al. (2014) found that Children with CP have been reported to have a significantly lower HRQoL in all domains compared with children with typical development, especially in the domain of motor function. Quality of life (QOL) is defined by the World Health Organization (WHO) as an individual's perception of his/her position in which he/she lives, and in relation to his/her goals, expectations, standards, and concerns of life in the context of the culture and value systems. It is a broad-ranging concept and incorporating in a complex way, the person's physical health, psychological state, level of independence, social relationships, personal beliefs, and relationship to salient features of the environment. Specific learning disability is a group of neurodevelopmental disorders which manifest as persistent difficulties in learning in childhood to efficiently read (dyslexia), write (dysgraphia), or do simple mathematical calculations (dyscalculia) despite normal intelligence, conventional schooling, intact hearing and vision, and adequate motivation and socio-cultural opportunity. (Karande & Kulkarni, 2009). Disability in a child, the basic component of a family, and accompanying challenges affect profoundly other members of the family and

may be an intensive source of anxiety. In members of family having to take care of the disabled child all day and for ages, physical and psychosocial health is influenced in a negative way (Yilmaz et al., 2013).

Today, the Gross Motor Function Classification System (GMFCS) is the principal way to classify gross motor dysfunction internationally (Compagnone et al., 2014). It describes the movement ability of children in one of five ordinal levels (and provides descriptions for each level across five age bands: < two years; two to four years; four to six years; six to 12 years; 12 to 18 years). Motor dysfunctions in children with CP result in limitations in their activities of daily living and participation in leisure activities, thereby adversely affecting their enjoyment and HRQoL (Palisano et al., 2011). Morris (2007) mentioned that unlike classifications based on motor type and topography, the GMFCS has been shown to be a valid, reliable, stable and clinically relevant method for classification and prediction (after the age of two) of motor function in cerebral palsy. Another study dichotomized children with CP aged 2.5 followed to 4.5 years of age into two groups (GMFCS level I – III vs. GMFCS level IV and V), and found that only the behavioural problem children with a GMFCS level I–III (Alsem et al., 2013).

The Manual Ability Classification System (MACS) provides a method analogous to the GMFCS for assessing the ability of children with cerebral palsy to handle objects (Eliasson et al., 2006) and the Communication Function Classification System (CFCS) assists in evaluating the communication capacity within ‘real-life’ situations for children with cerebral palsy (Hidecker, 2011). Use of the GMFCS, MACS and CFCS together allows for a comprehensive picture of functional performance in daily life for individuals with cerebral palsy to be drawn, to inform both research and clinical practice (Hidecker, 2011).

Taking care of these children, especially those who require special and long-term support, results in physical and mental stress for mothers (Kaya et al., 2010). There is much evidence to show that mothers who take care of disabled children suffer from more severe physical and psychological complications than mothers with healthy children (Laurvick et al., 2006). Rostami et al. (2013) found that the socioeconomic status, marital satisfaction, and subtypes of pervasive developmental disorders have a significant influence on the Quality of life of mothers of children with pervasive developmental disorders in Iran. There is no

doubt that these conditions can affect the Quality of life of mothers who have children with Cerebral Palsy (Gorter et al., 2009). It naturally follows that taking care of a disabled child has a profound impact on the Quality of life and health of mothers who are in charge of caregiving; however, its different dimensions and scales must be reviewed in each region or country based on those lifestyles (Davis et al., 2010). Quality of life (QoL) is widely used in health and medical studies to measure health status (Habashneh et al., 2012). Identifying the factors affecting Quality of life can enhance treatment, care, and rehabilitation programs (Soh et al., 2013). One of the major goals of all countries is to improve people's Quality of life and well-being (Prudente et al., 2010). Quality of life is a subjective concept that encompasses all conditions and aspects of human life (Nesterko et al., 2013). According to the World Health Organization, Quality of life is defined as the individual's perception of his/her position in life in the context of his/her culture and value systems in which he/she lives, and in relation to his/her goals, expectations, standards, and concerns (Susniene & Jurkauskas, 2009). Quality of life involves indicators such as good health, proper housing, employment, personal and family security, education and recreation, mental health, physical health, proper family life, proper social life, job security, and freedom (Sadeghi, et al., 2013).

Quality of life is a broad concept in social network of relationship that would lead to maintain a good quality of life and that indicates the increase of social networking (Bayatiani et al., 2011). It has been reported in multicultural comparative studies, underlying social factors, such as race, sex, religion, and the socioeconomic status of families with disabled children are among the critical factors that can cause problems while caring for these children (Soh et al., 2013). The present study concentrates on several individual and social factors to compare the Quality of life of mothers who have a child with CP and mothers with a healthy child in Iran. Receiving information about an impairment in a child's development seriously affects the functioning of the entire family. The family members face numerous challenges, and difficulties abound while everyone tries to adapt to the new situation. It is a heterogeneous group of movement and posture disorders caused by non-progressive damage to the immature brain. It may be accompanied by other disorders such as epilepsy, deficits in speech, hearing, vision, and intellectual disability (Kulak et al., 2006).

Kaya et al. (2010) suggested deterioration of mental health in mothers of CP causing them to experience more back pain which cause deterioration of health related Quality of life. All these suggest possible presence of Depression and affected Quality of life. But these results cannot be generalized to our population because different population has different characteristic. So the need of our study is to find out prevalence of depression & affection in Quality of life of mothers of children suffering from Cerebral palsy. Present study was done to evaluate the quality of life of mothers of children with cerebral palsy. Diwan et al. (2011) suggested that mother with disabled children have anxiety & depression which affects mother's Quality of life.

Diwan et al. (2011) showed that there is prevalent depression in mothers of children with Cerebral palsy and Quality of life especially role limitation due to physical health & emotional problems and social functioning are more affected than other components in our population. So different coping strategies and psycho-social programme must be designed and implicated to improve social and emotional well-being. There is also need for formulation of parents support group. Diwan et al., (2011) found that 70% of mothers of children with CP suffering from mild to moderate level of depression and have affected Quality of life. Our study has showed prevalent depression and affected Quality of life of mothers of children with CP.

Sajed et al., (2010) suggested that the birth of a developmentally disabled child is a family stressor and mothers often feel guilty and sense of responsibility because of their character qualities more than the other family members, hence, they involve in compensation strategies to overcome their children disability. Mothers of children with different levels of disability tolerate high level of stresses. Children with chronic medical conditions cause depression emotional and behavioural problems in their mothers. Mothers of cerebral palsy (CP) children, as an integral part of the team have a lot of social and emotional problems. Some studies focused on the status of mothers having Cerebral palsy children. In the study of Ones and his colleagues showed that, mothers having Cerebral palsy children had depressive symptoms and lower quality of life. In a research studied the relationship between children disability and mothers mental health (Singogo, 2015).

Sipal & Sayin,(2013) found that the prevalence of depression in 3 groups of mothers having: a) premature infants with the risk for developing CP, b) premature infants without risk of CP and, c) normal infants, was the same at the first year of children lives. Varni et al. (2005) told that child characteristics such as age, gender, severity of disease, and pain have been shown to influence parents report of children Quality of life in various chronic conditions, including Cerebral palsy. Previous studies provided conflicting evidence about the relationship of Quality of life to severity of motor impairment and suggested that domains related to physical symptoms may be more affected than social or emotional functioning domains. This may be attributable in part to the fact that physical aspects are more easily reported than psychological aspects. However, few studies examined the influence of other impairments in this population. Social contacts and activities with peers are reported to be reduced by chronic pain (Von et al., 2006).

Previous studies, mainly from the general population (Von et al. 2006) suggested that children from lower socioeconomic backgrounds have significantly more negative experiences of health and well-being, but there is insufficient evidence to determine whether a similar relationship holds for children with disabilities. Parents' views of their children's Quality of life may also be affected by the burden of caregiving and their own mental health and well-being (White et al., 2007). Studies on the Quality of life of children with Cerebral palsy have focused mainly on small groups of children selected from clinics with homogeneous degrees of impairment severity, rather than the spectrum of impairments, and little is known about the influence of associated impairments in this population, despite the high prevalence of such difficulties. Our population-based study aimed to determine whether the type and severity of the children motor function and associated impairments, as well as the family context (socioeconomic factors and parental stress), influence the children Quality of life, as reported by the parents.

Robitail et al. (2006) suggested to identify the factors associated with the lowest Quality of life in each domain, because it is important in clinical settings to be able to identify children more likely to have poor Quality of life. We hypothesized that the influence of impairment would differ according to the dimensions of Quality of life examined and that the factors associated with Quality of life would not be the same for different levels of impairment severity. We also expected parental stress to be associated with parents' proxy-



reports of children Quality of life. Aydın & Nur, (2012) mentioned that there has been a growing understanding that the family has an important role in the life of children with disabilities. Family-centered care was developed to facilitate the process of care of children with special needs and their families. Since then, it has been widely used in child health and afterward implemented to the pediatric rehabilitation. The acceptance of family-centered care and the emergence of new theories on motor development have influenced the management of children with cerebral palsy. The interventions have become more family- and function-focused, rather than child-focused.

There are a limited number of studies in the literature evaluating musculoskeletal system pain and the related factors that are observed in the mothers of the children with cerebral palsy (Kaya et al., 2010). Knowing the extent and the risk factors of the problems in the musculoskeletal system of these mothers is of importance to determine the support and the approach to be provided to this group. It is also important for the quality of the care and the rehabilitation support that is provided to the healthy children of these mothers. The incidence of neck pain and back and low back pain within the last one year and the depression scores in the mothers who had children with cerebral palsy were significantly higher than those values in the mothers who had healthy children. Prudente et al., (2010) state that the number of children, the age of the children with cerebral palsy, the functional level of the children and the depression level of the child were independent risk factors in the musculoskeletal system pain of the mothers. Studies in the literature reported that the quality of life was disturbed and the physical health also, who had children with cerebral palsy and who developed locomotors system pain., in particular, was negatively affected. As far as we know, there is only one detailed article in the literature related to musculoskeletal problems and the pain that developed in the mothers who had children with cerebral palsy (Kaya et al., 2010). In this aspect, the results of the current study are valuable.

Tekinarslan (2013) found on mothers who had children with muscular dystrophy, they found a correlation between back pain and daily life activities of the children. Ozel et al. (2009) suggested that the current study also supports the finding that as the functional dependency increases, the complaint of pain also increases in this patient group. Sixty-five

to ninety percent of the cases with cerebral palsy live until adult age, therefore, the care provided by the mother who had a child with cerebral palsy is a one-way, dependent and long-term process. The age of the children is important for the duration of this care. As the child grows, the physical load and requirements of the child increase and the parent ages. The present study found that the age of the mothers who suffered from the pain and whose children had CP was older. The studies in the literature have demonstrated that together with the increasing age, pain increases and the tolerance of the pain decreases (TeRzi & Tan, 2016). The degenerative changes that develop in the joints, together with the increasing age, might render the mothers in this group under the risk for the development of pain. It has been demonstrated that the depression levels in these mothers might be related to the type and severity of cerebral palsy (Ozel et al., 2009). Depression and chronic stress might cause physical symptoms related to stress in these mothers. The prolonged stress and depression might affect immunological functions by causing dysfunction and excessive stimulation in the neuro endocrinological stress response system (TeRzi & Tan, 2016). Tong et al. (2013) demonstrated the correlation between the symptoms of depression and the impairment in physical health and chronic pain. In the current study, the depression levels were correlated with the musculoskeletal pain that developed within the last one year. Parents of children with CP experience elevated levels of stress compared with the general population (Glenn et al. 2009). The increased musculoskeletal pain in these mothers was thought to be caused by the negative effects of chronic stress and the symptoms of depression on the physical health, in addition to the physical load to which they were exposed. (TeRzi & Tan, 2016) found the incidence of low back pain was 71.1% in female caregivers of children with physical disabilities and this ratio was lower in caregivers of the children without physical disabilities.

These mothers show high levels of stress, mental health problems, depression, anxiety, financial difficulties, negative emotions, self-blame, fear of child future problems, impaired physical performance, and fatigue or exhaustion (Zani et al., 2013). Quality of life is affected by factors such as beliefs, attitudes; as well as cultural, economic, social, and religious values. The specific role of the mother for the pregnancy and birth, child care, and education makes them experience more pressure. Therefore, they need more support (Yilmaz et al., 2013). These differences depend on the type of disability and lack of interest

of the child to the parents. Jalili et al. (2013) in a study evaluated the quality of life of mothers of children with severe cerebral palsy and factors affecting it.

The results showed that the quality of life of mothers of children with cerebral palsy is moderate. They showed that mothers of children with special needs have a low quality of life. Hagh et al. (2011) in a research evaluated the resiliency and quality of life of mothers of children with intellectual disability and the results showed that there is a positive and significant correlation between resiliency and quality of life. The results showed that most of the challenges that mothers are faced with include the risk of losing physical, mental, and social well-being are the cause of disable children and the time limit for dealing with family issues and financial burden and the lack of participation of appropriate recreational programs all are associated with this problem.

### **3.1 Study design**

This study aimed to find out the Quality of life of mothers of children with Cerebral palsy. For this reason a quantitative research model in the form of a cross-sectional type survey design is used .Cross sectional studies (also called a prevalence survey) aim at describing and quantifying the distribution of certain variables in a study population at point of time. It provides a snapshot of the health experience of a population at a given time (Hannan, 2007). I used this method so that the aim and objectives of the study can be fulfilled. The study was conducted between April 2016 to March 2017. Ethical permission was obtained from Institutional Review Board (IRB) and written informed consent was obtained from all participants.

### **3.2 Study site**

The study was conducted in Pediatric unit of Outpatient and inpatient Department at Center for the Rehabilitation of the Paralysed (CRP). In 2015 –a total number of 3562 patients take service from paediatric unit of CRP, from those total number of outpatient were 2820 (23764 appointments) and in-patients were 742 in the 14 day’s programme. Annual reporting, (2015).That’s why this area was chosen and the patients whose were exist here meet the inclusion & exclusion criteria of the study.

### **3.3 Study population**

The study populations were cerebral palsy children & their mothers, who came at CRP paediatric unit for rehabilitation service.

### **3.4 Sampling Procedure**

In the study convenient sampling technique was used here,considering the inclusion – exclusion criteria of the patients, who came to CRP paediatric unit.

### 3.5 Sample size

Sampling procedure for cross sectional study done by following equation-

$$n = \left\{ \frac{z - \frac{\alpha}{2}}{d} \right\}^2 \times pq$$

Here,

$$z - \frac{\alpha}{2} = 1.96$$

p=0.7 (from 70% prevalence)

q=1-p

d= 0.05

Calculating sample was 322, but 120 data was collected from 120 sample because that number was easy for me to collect and to analyse the data. So I selected those number, in additionally it was better for the study to compare with other study.

### 3.6 Inclusion criteria of mothers

1. Who has at least one CP children.
2. Who receive treatment for her children from CRP paediatric unit.
3. No age limitation.
4. Who are full time carer of her children.
5. Who are voluntarily agreed to participate in the study.

Inclusion criteria of mothers were composed of having a child with CP, living with the child (Yilmaz et al., 2013).

### Inclusion criteria of CP children

1. Age range between 1 to 12 years.
2. Both male & female.
3. Any type of CP, whose diagnosis is confirm by physician.

Mothers with CP children are put into classification as spastic (diplegic, quadriplegic, and hemiparetic) dyskinetic (including athetosis and dystonia), and mixed type according to this classification (Yilmaz et al., 2013).

### **3.7 Exclusion criteria of mothers**

1. Any Cognitive or psychological disorder of mothers that can prevent understanding of Questionnaire.
2. Any chronic disorder of mothers as Arthritis, Diabetes mellitus, Hypertension.

### **Exclusion criteria of children**

1. Children's above 12 years old.
2. Other disease like Autism, hydrocephalus, microcephaly, down syndrome, Erb Palsy.

Mothers of children with other neurological conditions like Erb's palsy, down syndrome, Autism etc were excluded (Diwan et al., 2011).

### **3.8 Data collection instrument and tools**

A questionnaire SF36 & a scale GMFCS & socio-economic informative questionnaire were used for data collection.

### **Measurement tools**

A socio-demographical informative questionnaire was developed by researcher to collect data. A Standardized questionnaire/tool named the Short Form-36 (SF-36) is a 36 item questionnaire which measures Quality of Life (QOL) across eight domains. The Gross Motor Function Classification System or GMFCS is a 5 level clinical classification system that describes the gross motor function of children with cerebral palsy.

### **SF-36**

The Short Form-36 (SF-36) is a 36 item questionnaire which measures Quality of Life (QOL) across eight domains, which are both physically and emotionally based and it is a structured, self-report questionnaire (Jenkinson et al., 2014). The eight domains that the SF36 measures are as follows: physical functioning; role limitations due to physical health; role limitations due to emotional problems; energy/fatigue; emotional well-being; social functioning; pain; general health. It is the most widely used measures to predict health-

related quality of life and it also help in showing the difference between subjects with variety of chronic conditions and between subjects with different level of severity of the same disease.

## **GMFCS**

The Gross Motor Function Classification System or GMFCS is a 5 level clinical classification system that describes the gross motor function of children with cerebral palsy on the basis of self-initiated movement abilities. Particular emphasis in creating and maintaining the GMFCS scale rests on evaluating sitting, walking, and wheeled mobility. Distinctions between levels are based on functional abilities; the need for walkers, crutches, wheelchairs, or canes / walking sticks; and to a much lesser extent, the actual quality of movement. The original version of the GMFCS was developed in 1927 (Palisano et al., 2007).

The original concept was developed collaboratively by Robert Palisano, Professor of Physiotherapy at Drexel University; Peter Rosenbaum, Professor of Developmental Pediatrics at McMaster's; Stephen Walter, Professor of Biostatistics at McMaster's; Dianne Russell; Ellen Wood; and Barbara Galuppi. GMFCS is now the standard in both North America and Western Europe for mobility assessment and ambulatory ability prediction for cerebral palsy children (Palisano et al., 2007).

### **GROSS MOTOR FUNCTION CLASSIFICATION SYSTEM**

LEVEL I - Walks without limitations

LEVEL II - Walks with limitations

LEVEL III – Walks using a hand-held mobility device

LEVEL IV -Self-mobility with limitations, may use powered mobility

LEVEL V - Transported in a manual wheelchair

The Gross Motor Function Classification

## **Validity**

Validity encompasses the entire experimental concept and establishes whether the results obtained meet all of the requirements of the scientific research method. In addition, validity is the extent to which a test measures what it claims to measure. It is vital for a test to be valid in order for the results to be accurately applied and interpreted. Validity is concerned with the accuracy of scientific findings.

## **Reliability**

The idea behind reliability is that any significant results must be more than a one-off finding and be inherently repeatable. Reliability refers to the consistency of a measure. A test is considered reliable if we get the same result repeatedly.

## **Reliability and Validity of SF36**

SF36 is the most useful scale for measurement of Quality of life or health status and wellbeing of a person. This is also translated in Bangla by linguistic for better understanding of a person. The SF-36 was best correlated with the Expanded Disability Status Scale (EDSS) and the Ambulation Index as a physical functioning scale. Quality of life of mothers also detected by this Questionnaire. Most of the research that are used here also follow this Questionnaire for detect Quality of life of mothers of children with cerebral palsy and this study also use this Questionnaire (Okurowska et al., 2011).

## **Reliability and Validity of GMFCS**

The GMFM was designed for use by paediatric therapists who are able to assess motor skills in children. GMFCS is most useful scale for measurement of functional impairments of children. Most of the research that are used here also follow this scale for detect functional impairments and this study also use this scale (Okurowska et al., 2011).



## **Pilot study**

Pilot study is a preliminary, smaller version of a proposed research study, conducted to refine the methodology. It should be as similar to the proposed study as possible, using similar subjects, the same setting, and the same techniques of data collection and analysis to detect any problems which can be corrected. A pilot study was carried out prior to the main data collection procedure to prepare the questionnaire for the study. So, a pilot study is important to carry out before beginning the main study.

Researcher took one week for pilot study and visited CRP pediatric unit of Physiotherapy Department. Researcher meet with the CP children and their mothers whose are involved in the study and this pilot study was performed on 5 participants.

## **3.9 Data collection procedure**

Before data collection, researcher was first introduced herself to the participants & took verbal consent. Then provided written consent form to the participant, and after signed the consent form, data was collected through a questionnaire from the participants by face to face conversation. In that way questionnaire was presented and data was completed. In the questionnaire, there was participant's demographic information including age, sex, area, education and sibling of cerebral palsy children, along with questionnaire of SF-36 and a five level of scale GMFCS. Data was collected from patient present in paediatric unit (outpatient and inpatient) of CRP; Savar and researcher collected data from 27 June 2016 to 20 October 2016.

## **3.10 Data analysis**

After completing the initial data collection, every questionnaire was checked again to find out any mistake or unclear information. Then data was analysed through Statistical package of social science (SPSS) version 20 and data was levelled in Microsoft Excel worksheet and arranged in results. Then data was analysed through descriptive statistics and descriptive statistics was used to fulfil research objectives.

### **3.11 Ethical considerations**

The proposal of the dissertation including methodology was submitted presented to the Bangladesh Health Professions Institute (BHPI) & approval was taken from Institutional Review Board (IRB).The whole process of this research project was done by following the Bangladesh Medical Research Council (BMRC) guidelines and World Health Organization (WHO) Research guidelines.

Verbal and written inform consent was taken from every patient. And ensure every patient that they can leave any time during data collection, & it was ensured that participants were not influenced by data collector. The researcher strictly maintained the confidentiality regarding participant's condition and treatments. The study was conducted in a clean and systematic way. Every subject had the opportunity to discuss their problem with the senior authority or administration of CRP and have any questioned answer to their satisfaction.

In the present study, HRQoL was assessed by using SF36 among the 120 participant mothers of children with cerebral palsy. This study found the socio-demographic information of the participants.

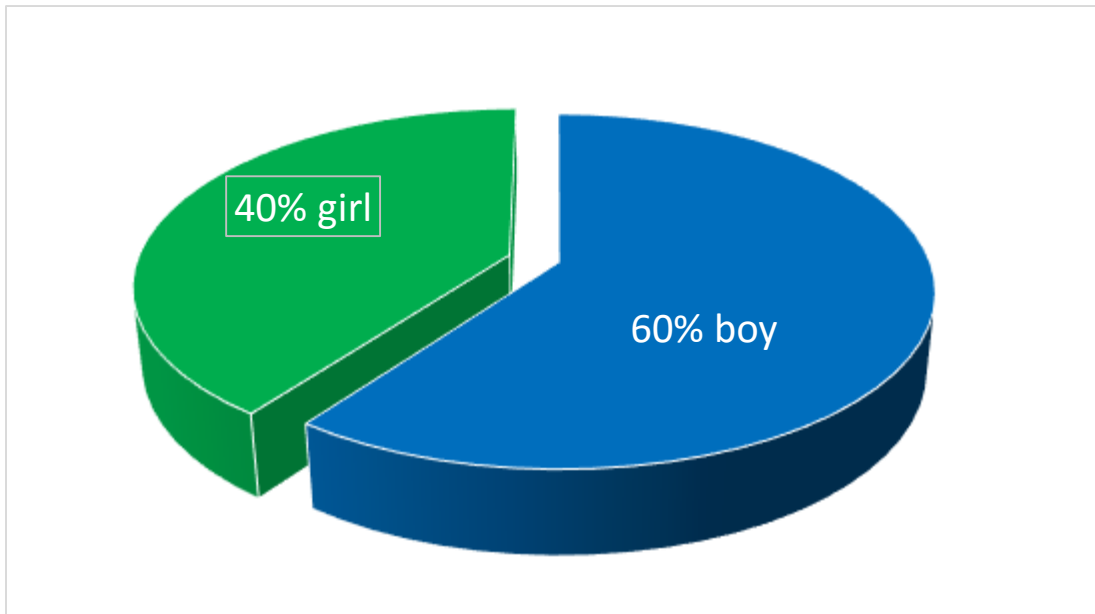
**Table 1: Table shows the socio-demographic information of the participants**

<b>Feature</b>	<b>Age</b>
<b>Age of the mothers</b>	
Mean	21.40
SD	4.410
Median	20.00
Minimum-Maximum	14-37
<b>Age of the children</b>	
Mean	4.44
SD	2.530
Median	4
Minimum-Maximum	2-12

<b>Feature</b>	<b>Number</b>	<b>Percentage</b>
Housewife	120	
<b>Area of living</b>		
Urban	60	61.20
Rural	40	42.10

#### 4.1 Ratio of boy and girl among CP children

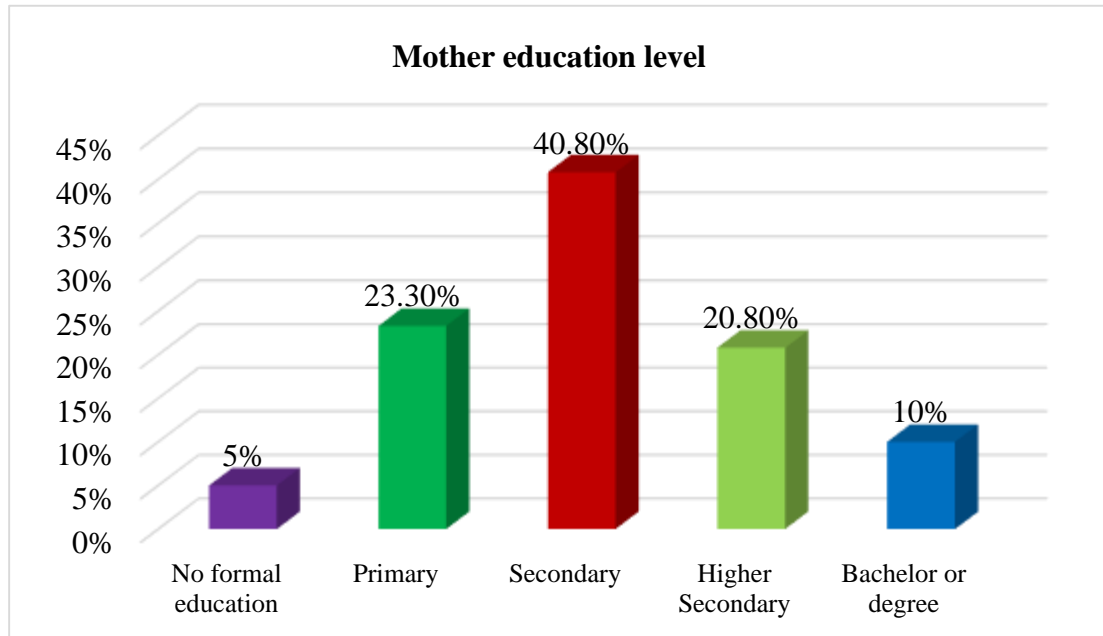
The mean age of the child was 4.42 years with a standard deviation of 2.50. Majority of the child (28.3%) was 2 years old. A total 60% children were boy, 40% children were girl.



**Figure-1: Gender ratio of the participants.**

## 4.2 Education level of the mothers

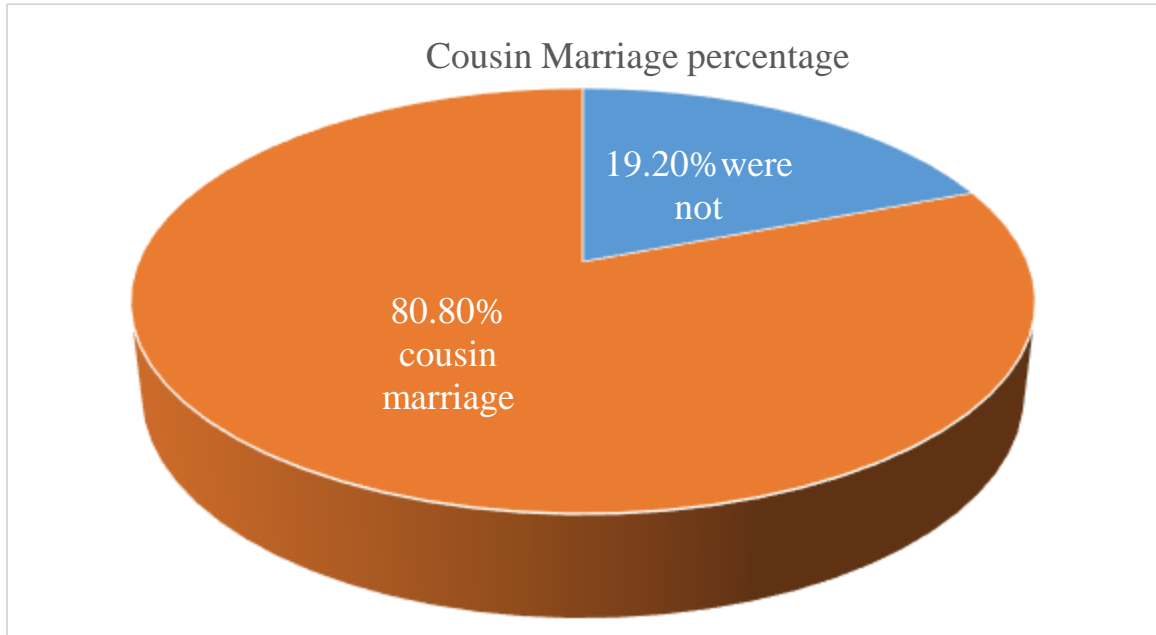
Out of the 120 participants mother, education status showed that 5% (n=6) mothers were no formal education, 23.3% (n=28) completed primary education, 40.8% (n=49) completed secondary education, 20.8% (n=25) completed Higher Secondary education, and 10% (n=12) completed Bachelor or degree education. (Figure-3).



**Figure-2: Percentage of mother educational level**

### 4.3 Cousin marriage of the participants

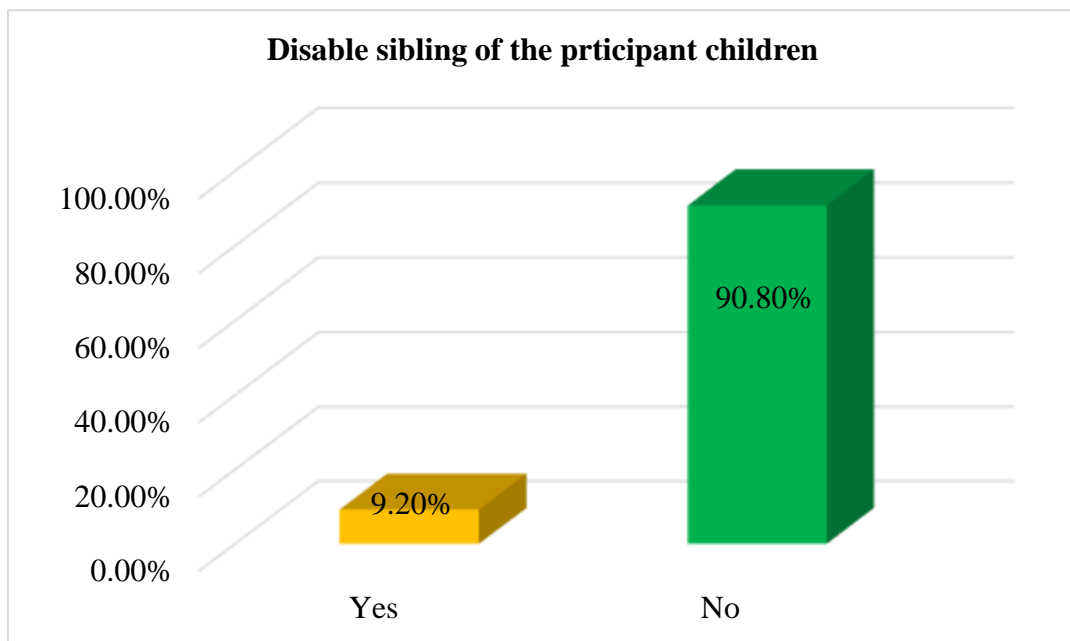
All 120 the participant 19.20% (n=23) was got cousin marriage and 80.80% (n=97) was not cousin marriage (Figure-4).



**Figure-3: Cousin Marriage percentage.**

#### 4.4 Any other disable child of the participants (sibling)

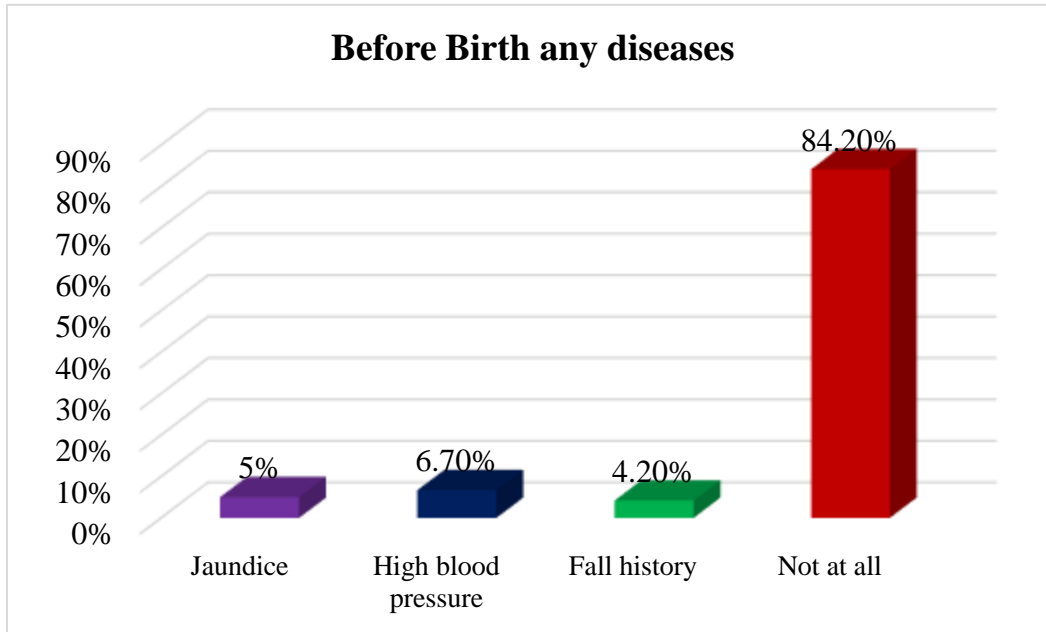
Among 120 participants of mother, 9.20% (n=11) were found more than one disable child and 90.80% (n=109) are not (Figure-5).



**Figure-4: Percentage of other disable children of the participant mothers**

#### 4.5 Diseases condition of mother during pregnancy

During pregnancy, 5% were suffered from jaundice, 6.70% were from High blood pressure, 4.20% were from fall history, and 84.20% were not suffered from any diseases, among 120 participants of mother. So we see that maximum mothers were suffered from High blood pressure.

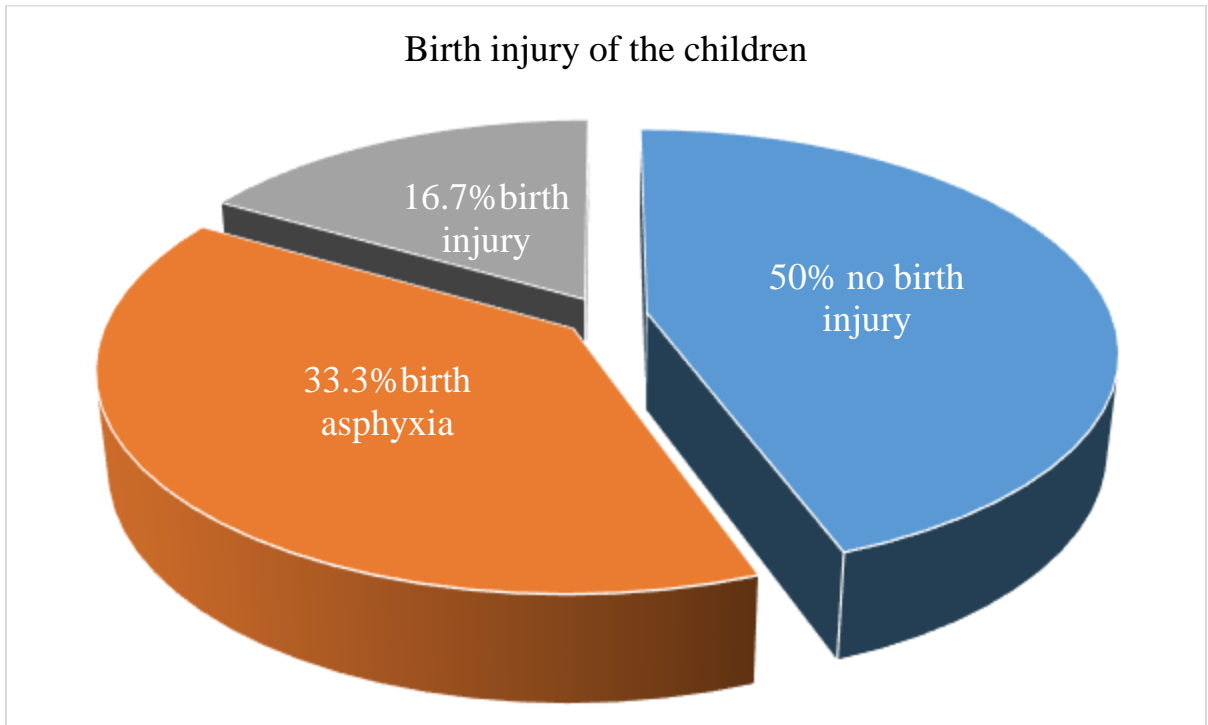


**Figure-5: Percentage of diseases condition of mother during pregnancy.**



#### 4.6: Birth injury of the child

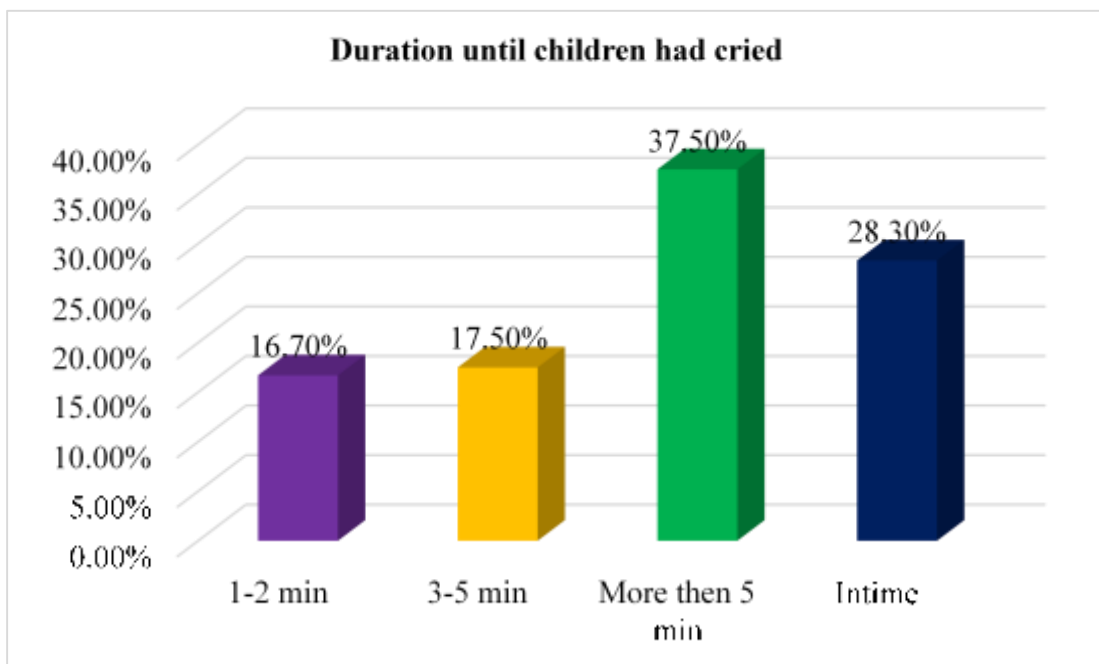
Out of 120 participants, 16.7% (n=20) participants had present birth injury, 33.3% (n=40) had present birth asphyxia and 50% (n=60) had not present.



**Figure-6: Birth injury percentage of the children**

#### 4.7: Duration until children had cried from birth period

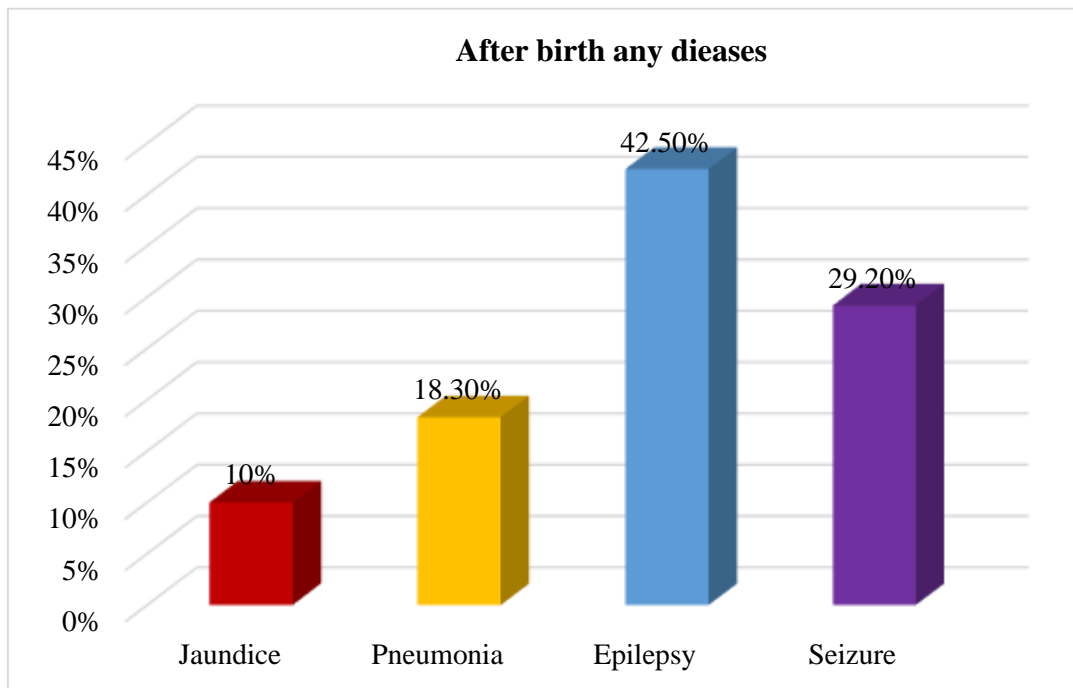
The figure showing duration until child's cried. From 1-2min, was 16.7% (n=20), 3-5min was 17.5% (n=21), and more than 5min, was 37.5% (n=45) and in time was 28.3% among 120 participants.



**Figure-7: Duration until children had cried & percentage of those children**

#### 4.8 Diseases that developed after birth of CP children

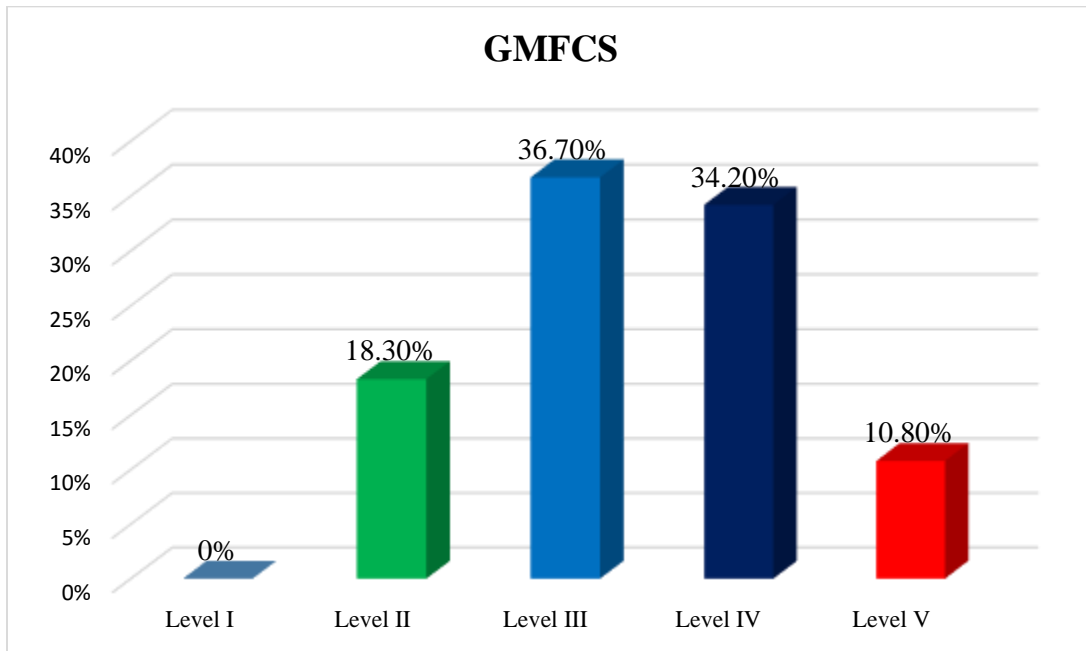
Among 120 participants of CP child maximum children's were suffered from Epilepsy (42.50%), some of children (29.20%) were from seizure, some of (18.30%) from pneumonia, and minimum children (10%) were from jaundice.



**Figure-8: Diseases condition of CP child after birth.**

#### 4.9 GMFCS scoring of the CP child

Among 120 participants of CP child, 18.30% was remain Level-II, 36.70% was in Level-III, 34.20% was in Level-IV, 10.80% was in Level- V. From this it is clear that maximum children were in level-II and some of the children were in level-V and no children were in level-I.



**Figure 9: GMFCS - Scoring**

## 5: SF36 scoring among the participants mother

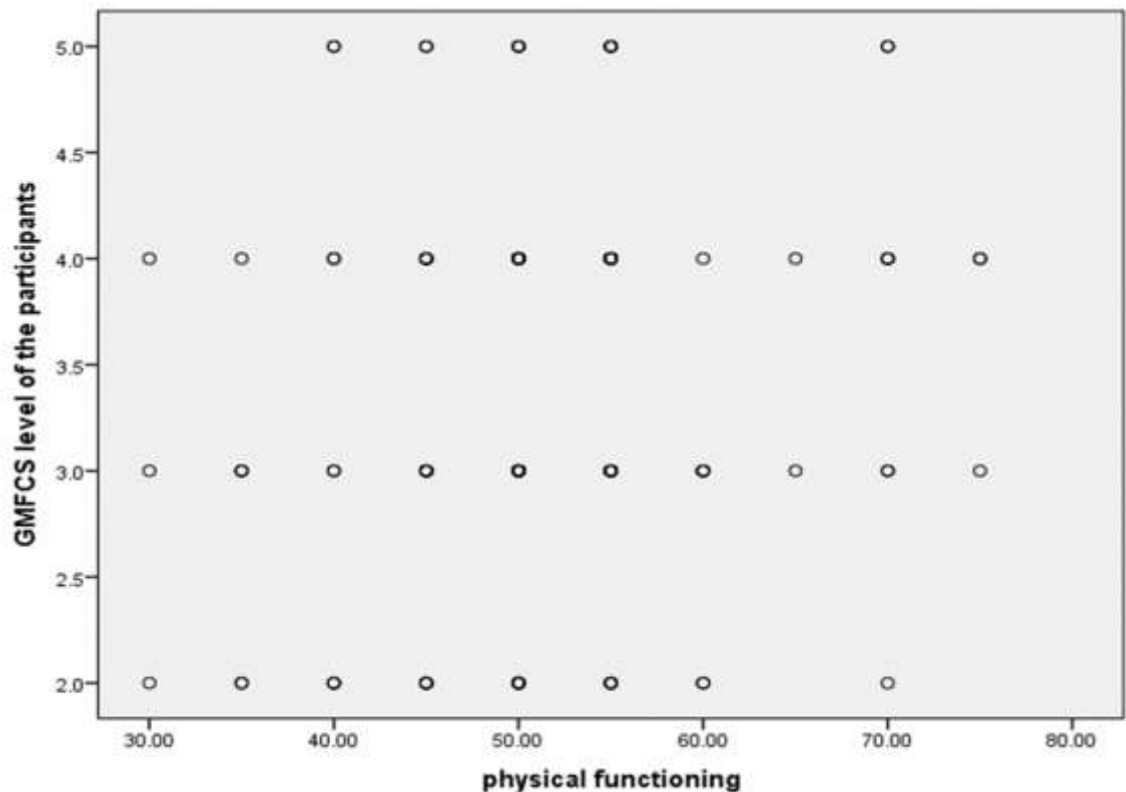
Variable	Mean	SD	Maximum	Minimum
Physical functioning	51.21	9.5	75	30
Role limitation due to physical health	64.27	5.26	93.75	50
Role limitation due to emotional problem	62.15	8.15	83.33	00
Energy or fatigue	47.55	6.08	62.50	31.25
Emotional well-being	55.29	8.10	70	25
Social functioning	92.60	9.24	100	62.50
Pain	87.54	13.57	100	55
General health	46.29	8.99	70	35

**Table-2: SF36 scoring among the participant mothers**

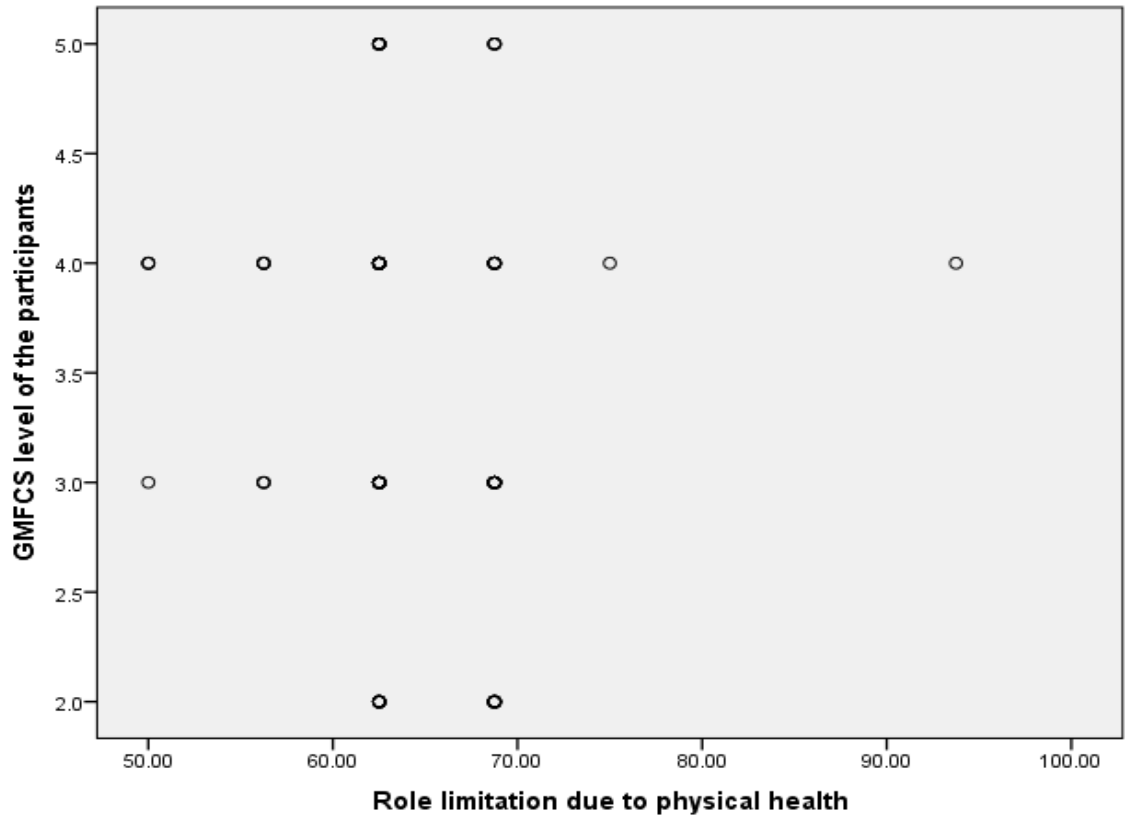
The SF-36 questionnaire is easy to apply (from home, hospital, by phone etc.) and it doesn't require lot of time to answer the questions and process the data. And it is easy to evaluating individual patients. The SF 36 consists of eight scaled scores, which are the sums of the questions in their section. This data was also analysed by using SPSS version 20. From 120 participants the minimum & maximum percentage of physical functioning was 75% & 30%, role limitation due to physical health was 93.75% & 50%, role limitation due to emotional problem was 83.33% & 00%, energy or fatigue was 62.50% & 31.25%, emotional well-being was 70% & 25%,social functioning was 100% & 62.50%,pain was 100% & 55%, general health was 70% & 35%.And from these section,the mean score of physical functioning was 51.21%, role limitation due to physical health was 64.27%, role limitation due to emotional problem was 62.15%, energy or fatigue was 47.55%, emotional

well-being was 55.29%, social functioning was 92.60%, pain was 87.54%, and lastly general health was 46.29%. And standard deviation of PF was 9.5%, RP was 5.26%, RE was 8.15%, E was 6.08%, EW was 8.10%, SF was 9.24%, P was 13.57%, and GH was 8.99%. When the score is near about 100, like 70, 80, 90, it means the quality of life of mother is good & when the score is poor like 30, 40, it means the quality of life of mother is poor. And here maximum percentage was, 70, 80, 90. And from scatter dot diagram there was no correlation between GMFCS level and 8 domains of SF36 score. So from the study we understood that the level of GMFCS score cannot relate with poor Quality of Life.

## 6: Relationship between GMFCS and QoL of mothers



**Figure 4.10: Absolutely no relation between GMFCS & HRQoL**



**Figure 4.11: Absolutely no relation between GMFCS & HRQoL**

So from scatter dot diagram it was clear that, there was no relationship between GMFCS & HRQoL

This discussion is based on among 120 participant's mother & their children.

According to the results of the present study, the mean age of the mothers was 21.40 that means most of the participant mothers age range were (18-26) years, so age was not the main factor for giving birth of a CP child. One study conducted in America showed that, mean age of the mothers was  $37.9 \pm 11.4$  years (Allah et al., 2012). From the study we see that, mean age of mothers was comparatively lower than other study. So young age of the mothers can risk for developing CP children and can affect quality of life of mothers.

In this study maximum age of the mothers was 32 years. In the United States, birth rates for women in their 30s are at the highest levels in three decades. However, an older mother have chance to increase risk for miscarriage, birth defects, and pregnancy complications such as twins, high blood pressure, gestational diabetes, and difficult labours. Some studies showed that there may be a greater chance of pregnancy complications of the babies of older women than babies of younger women. Nabors conducted a research on "Maternal age and parity in relation to Cerebral palsy in their infants" showed that the patient who was more than 35 years old is more likely to produce a child with cerebral palsy than younger women (Brown et al., 2008). So from this study it also clear that CP can developed from the middle age of the mothers and their Quality of life can hamper for this reason.

Educational status of the mothers were not very well and most of the participants were completed higher secondary and 10% were completed Bachelor degree. From another study in U.S.A showed that 6.7% mothers were completed H.S.C (Hwang et al., 2011). Another study in Australia found that, 1.5% were completed primary level, 37.2% high school level, 22.1% trade certification and 29% university. There is a big difference in this study in case of bachelor degree (19%). On the other hand there is a similarity in compare of higher secondary education, because the mothers from this study and other study most of them completed secondary education. So, less education can effect for continuing good life.



Birth injury is a common problem for developing CP children. From the study 15% children were birth injury, 35% were birth asphyxia and 40% were not present any birth defect. In India one study showed that, during birth 26.3% children had birth asphyxia (Souza et al., 2006). In addition, another study in Netherland showed that 17.3% children had birth asphyxia during birth (Toorn et al., 2007). There birth injury is less than birth asphyxia and this is risk for developing CP children.

From the study among 120 participant mothers 19.20% were cousin marriage & 80.80% were not. The union between two people genetically related by descent from a common ancestor is called consanguineous marriage. Any marriage between relatives less close than siblings (brothers and sisters) or parents and offspring are not necessarily outlawed, but the dividing line between legal and illegal is vague and varies between countries. Consanguineous marriage is still high in Egypt (35.3%), especially among first cousins (86%). However the frequency varies by region. Also it was higher in rural areas (59.9%) than in semi-urban and urban areas (23.5% & 17.7% respectively) (On the other hand first cousin marriage is also risk for developing cerebral palsy, include birth after fewer than 32 weeks gestation, birth weight of less than 5 lb with intrauterine growth retardation, intracranial hemorrhage and trauma and about 10 to 20% patients (Chen et al., 2013). In most African societies consanguineous marriages are not allowed. But in Japan, India, Pakistan and the Middle East consanguineous marriages is high. Children birth from such close marriages showed various types of genetic disorders such as birth defects, mental retardation deafness and blindness. So first cousin marriage can risk for developing CP children because of genetic problem.

A study by Garel et al., (2007) showed that, premature or post term birth was the main problem reported by mothers at one year after giving birth a disabled children. These prematurity were for fatigue, depressed mood and physical symptoms of the mothers. This condition of the mothers were also responsible for developing various disease condition of the children. From this study after birth the children were suffered from various diseases like, 42.50% from Epilepsy, 29.20% from seizure, 18.30% from pneumonia, and 10% from jaundice. That disease were also related with any abnormality and also the sign & symptom of CP children. A Study showed that after birth various complication were developed in participants. Those were pneumonia 12.3%, seizure 23.3%, jaundice 10.7%, dehydration

1.3%, others 6.7%, nil 10.3%, dehydration. In India, a study presented that presence of neonatal seizure was 7.9% (Souza et al., 2006). So, disease condition after birth can also risk for developing CP & this can affect Quality of life of CP children & their mothers.

Our study includes gross motor functional classification system and here enables of classified as one to five level. Observation of motor skill is the main function of (GMFCS). From this study, most of the children (36.70%) were in level II, and some of children (10.80%) were in level V. So the highest number of CP children had GMFCS level-III and lowest number had level-IV in comparing with other study where another study found the highest number of children had level –II and lowest number in level- IV. So there is a similarity because both study show the lowest number in level –IV (Okurowska et al., 2011). Also sajed et al, (2009) in their study they showed that the difference among the healthy parents and the cerebral palsy child parents are depends on the severity of disease using Gross motor functional classification system (GMFCS) there were no significant difference of depression in both group. Edwards et al. (2011) found that, the most important factor for those child are functional capabilities, which are mostly dependent upon the family members. This dependency require less amount of time for the family members for any work and also for effort or resources to care for him/her. Although care is a normal part of being a parents of a young child, this role has a completely different mainly when the child has functional limitation and possible long-term dependence. Therefore, the task of caring for a disabled child at home can be difficult for the parents, so there need specialized health care. It is very normal that, care of a disabled child usually become an important factor & that can disrupts the regular functioning of a family, especially mother. These disable children require regular visit to specialist and long-time rehabilitation programme and special consultations (Okurowska et al., 2011). In one study found that the most numerous group of children were used an orthopedic device and a rehabilitation wheelchair, if there was limitation with walking.

Quality of life mother is decreases while the child is growing up. However, we could not detect any association between Quality of Life of mothers with functional level of CP children, body involvement of CP child, educational status of mothers, and number of children.

Diwan et al. (2011) found that, studies investigating QoL and related factors in mothers of children with CP report different findings. Some studies report that Quality of life of mothers with CP children is affected negatively. While Quality of life of mothers is reported to be associated with educational status and functional levels others assert that no correlation is present between Quality of life of mothers and functional levels of CP children. In my study notice that more than half of the parents with cerebral palsy children describe their quality of life very well, they were satisfied with their health and some of the people among them describe that they are “neither satisfied nor dissatisfied.

While Quality of Life of mothers is reported to be associated with depression, anxiety, educational status, and functional levels, but others assert that no correlation was present between Quality of Life of mothers and functional levels of CP children. In one study performed by Diwan et al. (2011) 70% of mothers with CP children were reported to have mild-to-moderate depression, and the depression was reported to have a negative effect on Quality of Life of mothers. Another study conducted by Ones et al. suggested that, Quality of Life of mothers with CP children is affected negatively, Quality of Life is negatively correlated with levels of depression and education in mothers and no correlation is present between Quality of Life and functional levels. From this study there was no relation between functional level of the children and quality life of mother. In addition and functional skill and the Quality of Life of mother was not significantly influenced by the level of education of the mothers of children with cerebral palsy.

In another study. Kaya et al. (2010) reported that the deterioration of mental health in mothers with CP children gives rise to experiencing further low back pain by mothers, leading to more deterioration in Quality of Life. From one study, it was reported that decrease the social activities of mothers with disable children. Disability in a child, is the

basic component of a family, and accompanying challenges affect profoundly other members of the family and may be an intensive source of anxiety, however, social support had a very significant impact, because it modified the relationship between the child's function and the depressive symptoms in the mother. As a result of cultural impacts in Turkey, mothers mostly take over the responsibility for disabled children and have to be interested in the challenges stemming from the disability alone for a long time. Therefore, we consider that physical and emotional health status of mothers is poorly affected. Present studies indicate that Quality of life of mothers of CP children is affected negatively, but the factors concerning Quality of life and related factors are controversial. In our study, it was determined, as consistent with the literature, Quality of life especially mental components of mothers with CP children, and it is definitely deteriorated, and high levels of depression affect negatively Quality of life of mothers. It is revealed that the quality of life of parents of healthy children are significantly compared with the cerebral palsy children parents, also physical functioning, mental state, social relationship and environment were significantly higher in group of parents with healthy children in compared with cerebral palsy children.

From 120 participants the minimum & maximum percentage of physical functioning was 75% & 30%, role limitation due to physical health was 93.75% & 50%, role limitation due to emotional problem was 83.33% & 00%, energy or fatigue was 62.50% & 31.25%, emotional well-being was 70% & 25%, social functioning was 100% & 62.50%, pain was 100% & 55%, general health was 70% & 35%. And from these section, the mean score of physical functioning was 51.21%, role limitation due to physical health was 64.27%, role limitation due to emotional problem was 62.15%, energy or fatigue was 47.55%, emotional well-being was 55.29%, social functioning was 92.60%, pain was 87.54%. This is for our culture, our area like urban or rural, in social functioning and bodily pain here maximum result is good because in our country here mother give more priority to their children otherwise to go or participate any cultural programme, or anywhere. Overall Quality of life of mothers was lower particularly in general health, comparatively higher in social functioning in comparing with other study. Another study showed the mean score and SD of physical functioning 51.83 & 23.10, bodily pain 59.10% & 29.14%, role limitation due

to physical health 54.07% & 33.32%, health perception 50.11% & 44.08%, social functioning 51.20% & 19.45%, mental health 53.62% & 22.50%, role limitation due to emotional problem 45.44% & 40.41%, vitality 53.39% & 26.07%.(Yilmaz et al., 2013).There is similarity & dissimilarity of this study in comparing with others. This can affect the Quality of life of mothers & Quality of life of mothers is assess only by this point. Lastly, I think growing up a cerebral palsy child is a major challenge for the entire family. Parents with cerebral palsy child require health care facilities more positively, we thought that effective rehabilitation programmes should provide sufficient opportunities for children, and repeated follow up interviews where not only information require for the children's disabilities but also psychological support for the mother.

Complete accuracy is not possible in any research so that some limitation may exist. Regarding this study, there were some limitations or barriers to consider the result of the study as below:

The small sample size may constitute a limitation as to the general ability of findings from this study. Other limitation of this study was its short duration, because here exist some course work of other subject & placement of 3 month and data were collected just from one centre. So the result might be generalized lack ability. The samples were collected only from the selected area at Centre for the Rehabilitation of the paralysed (CRP). So the result of the study could not be generalized to the whole population in Bangladesh. Only find out the results about QoL of mothers of CP children. So the results of the study was not compare with other disable children.

### **6.1 Recommendation**

In future, larger sample size is recommended to assess the Quality life of mother with cerebral palsy children in Bangladesh. Also compare the quality of life of mothers of children with cerebral palsy with that of mothers of children with other forms of disability and find out proper solution, so that mothers willingly give information about their child. In additionally conduct the study in large community and other institute.

### **6.2 Conclusion**

Parenting a child with cerebral palsy needs an ocean of patience, talent, courage and energy. When they lack in any of the aspect, the process becomes challenge for them. Parents need respite care which may be assisted by family members (Sridhar & Nirmala, 2015).Cerebral palsy is one of the most common congenital disorders of childhood.GMFCS is the measuring tool of the functional level of these children. Maximum children had lower level of functional status and we general people sometime think that this poor functional level can affect the Qol of mothers, but parents of children with cerebral palsy describe their quality of life as good and are satisfied with their health. They have adapted to this situation and accepted it and from this study we see that there is no relation between GMFCS and Quality of life of mothers. We must keep in mind that most of the difficulties are mainly due to financial problems rather than inadequate preparation to care for the child or lack of understanding of the disease.

Therefore, in planning a rehabilitation program for CP children, and also for mothers should be evaluated in detail. It is considered that mothers, undertaking the most significant role in the rehabilitation and caring for the child, should be treated the CP children in a better way. Additionally, mothers should be encouraged to take part in social activities related to their interests, and those with depressive symptoms should be supported psychologically.

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## APPENDICES

February 17, 2016  
The Chairman  
Institutional Review Board (IRB)  
Bangladesh Health Professions Institute (BHPI)  
CRP-Savar, Dhaka-1343, Bangladesh

**Subject: Application for review and ethical approval.**

Sir,

With due respect I would like to draw your kind attention that I am a student of Bachelor of Science in Physiotherapy at Bangladesh Health Professions Institute (BHPI)- an academic institute of CRP under Faculty of Medicine of University of Dhaka (DU). I have to conduct a thesis entitled, "Quality of Life of Mothers of Children with Cerebral Palsy" under honorable supervisor, Firoz Ahmed Mamin, Assistant Professor, Department of Physiotherapy, Bangladesh Health Professions Institute (BHPI), CRP, Savar, Dhaka. The purpose of the study is to find out the Health Related Quality of Life of Mothers of Children with Cerebral Palsy. Questionnaire will be used that will take about 20 to 30 minutes. Data collectors will receive informed consents from all participants. Any data collected will be kept confidential.

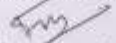
Therefore I look forward to having your kind approval for the thesis proposal and to start data collection. I can also assure you that I will maintain all the requirements for study.

Sincerely yours,

*Basona Akter Shanta*

Basona Akter Shanta  
Bachelor of Science in Physiotherapy (B. Sc. PT)  
Session: 2011-2012. DU Reg. No: 1716  
BHPI, CRP, Savar, Dhaka-1343, Bangladesh

Recommendation from the thesis supervisor

  
Firoz Ahmed Mamin  
Assistant Professor  
Department of Physiotherapy  
BHPI, CRP, Savar, Dhaka

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



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

Ref. CRP-BHPI/IRB/04/17/50

Date: 01/04/17

To  
Basona Akter Shanta  
4<sup>th</sup> year B.Sc. in Physiotherapy  
Session: 2011-2012, DU Reg. No.: 1716  
BHPI, CRP, Savar, Dhaka-1343, Bangladesh

**Subject:** Approval of the thesis proposal – “Quality of Life of Mothers of Children with Cerebral Palsy”.

Dear Basona Akter Shanta,

The Institutional Review Board (IRB) of BHPI has reviewed and discussed your application on February 17, 2016 to conduct the above mentioned thesis, with yourself, as the Principal investigator. The Following documents have been reviewed and approved:

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

Since the study involves answering a questionnaire: SF-36, that takes 20 to 30 minutes, have no likelihood of any harm to the participants, the members of the Ethics committee has approved the study to be conducted in the presented form at the meeting held at 08:30 AM on February 25, 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

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

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

July 24, 2016

The Head of the Physiotherapy Department,  
Centre for the Rehabilitation of the Paralysed (CRP)  
Chapain, Savar, Dhaka-1343.

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

**Subject:** Seeking permission of data collection to conduct my research project.

Dear Sir,

With due respect and humble submission to state that I am Basona Akter Shanta, student of 4<sup>th</sup> Professional, B.Sc. in Physiotherapy at Bangladesh Health Professions Institute (BHPI). According to course curriculum, I have to conduct a research for the partial fulfillment of our degree. My research project entitled on "Quality of life of mother of children with cerebral palsy" under the supervision of Firoz Ahmed Mamin, Assistant Professor, Department of Physiotherapy & BHPI, CRP. So I need to take permission to collect data for my research project from the inpatients and outpatients of paediatric unit, Physiotherapy department CRP - Savar. I would like to assure that anything of my study will not be harmful for the participants.

I, therefore, pray & hope that you would be kind enough to grant my application & give me permission for data collection and oblige thereby.

Sincerely Yours

Basona Akter Shanta

Basona Akter Shanta

4<sup>th</sup> Professional B.Sc. in Physiotherapy

Roll-13, Session: 2011-2012

Bangladesh Health Professions Institute (BHPI)

Forwarded  
24.07.16

Mr. Obaidul Haque  
Assistant Professor & Head of the Department  
Department of Physiotherapy  
Bangladesh Health Professions Institute (BHPI)  
C/O, Chapain, Savar, Dhaka-1343

Firoz Ahmed Mamin  
BPT (U) MSc in Orthopedics (Senior)  
Assistant Professor  
Department of Physiotherapy  
BHPI CRP, Savar, Dhaka

Approved  
Please contact with  
Suhraj Sultana, incharge  
Reed. Physiotherapy services  
as a counterpart of your  
for data collection process.  
24/07/16  
Call if  
24/07/16

Obaidul Haque  
24/07/16  
CRP, Chapain, Savar, Dhaka

## Consent Form

Assalamualaikum\ Namashker,

I am Basona Akter Shanta, 4<sup>th</sup> Professional, B.Sc. in Physiotherapy student at Bangladesh Health Professions Institute (BHPI) under the Faculty of Medicine, University of Dhaka. To obtain my Bachelor degree, I have to conduct a research project and it is a part of my study. My research title is “**Quality of life of mother of children with cerebral palsy**” To fulfil my research project, I need to some information from you to collect data. So, you can be a respected participant of this research and the conversation time will be 20-30 minutes. I would like to inform you that this is a purely academic study and will not to be used for any other purposes. I assure that all data will be kept confidential. Your participation will be voluntary. You may have the rights to withdraw consent and discontinue participation at any time of the experiment. You also have the rights to reject a particular question that you don't like.

If you have any query about the study, you may contact with my supervisor Firoz Ahmed Mamin, Assistant professor, Dept. of Physiotherapy, BHPI, CPR, Savar, and Dhaka-1343.

Do you have any questions before start this session?

So, I can proceed with the interview.

Yes  No

Signature of the participant and Date .....

Contact number.....

Researcher signature and Date.....

Signature of the Witness and Date.....

## সম্মতিপত্র

আসসালামুআলাইকুম \ নমস্কার

আমি বাসনা আক্তার শান্তা, ৪র্থ পেশাগত, বি এস সি ইন ফিজিওথেরাপি এবং বাংলাদেশ হেল্থ প্রফেসন্স ইন্সটিটিউট (বিএইচপিআই), ঢাকা বিশ্ববিদ্যালয়ের মেডিসিন অনুষদের অধীনে একজন ছাত্রী। আমার ব্যাচেলর ডিগ্রী প্রাপ্তির জন্য, আমার একটি গবেষণা প্রকল্প পরিচালনা করতে হবে এবং এটা আমার পড়াশোনার একটি অংশ। আমার গবেষণা প্রকল্পটির শিরোনাম হচ্ছে “ সেরিব্রাল পালসি শিশুদের মায়েদের জীবন মান”। এই গবেষণার মাধ্যমে আমি সেরিব্রাল পালসি শিশুদের সঙ্গে তাদের মায়েদের জীবন মান এবং শিশুদের বয়সের সাথে বিভিন্ন কাজকর্মের সম্পর্ক দেখবো। আমার পড়াশোনার এই প্রকল্প পূরণকল্পে, আমার কিছু তথ্য সংগ্রহ করা প্রয়োজন। সেজন্য, আমি আপনার কাছ থেকে ২০-৩০মিনিট সময় নিব। আমি আপনাকে অবহিত করছি যে, এটি একটি একাডেমিক গবেষণা এবং অন্য কোন উদ্দেশ্যে ব্যবহার করা হবে না। আমি আশ্বস্ত করতে চাই যে, সব তথ্য গোপন রাখা হবে। আপনি যে কোনো মুহূর্তে সম্মতি প্রত্যাহার করতে পারেন, এছাড়াও আপনি যেটি পছন্দ করেন না সেটা উত্তর না দেওয়ারও অধিকার আছে। যদি আপনার কিছু জানার থাকে তাহলে আমার সুপারভাইজার ফিরোজ আহমেদ মমিন ( অ্যাসিস্ট্যান্ট প্রফেসর, ফিজিওথেরাপি ডিপার্টমেন্ট) স্যার কে জিজ্ঞাসা করতে পারেন।

শুরু করার আগে নার কি কোন প্রশ্ন আছে ?

সুতরাং, আমরা ইন্টারভিউর দিকে এগিয়ে যেতে পারি। অ্যা

হ্যাঁ  না

অংশগ্রহণকারী স্বাক্ষর ও তারিখ .....

মোবাইল নাম্বার.....

গবেষকের স্বাক্ষর ও তারিখ .....

স্বাক্ষীর স্বাক্ষর ও তারিখ .....

## Questionnaire -English

**Title: Quality of life of mother of children with cerebral palsy.**

<b>Part-1: Patient's Identification</b>	
1.1	Patient code:
1.2	Date of data collection:
1.3	Children's Age:
1.4	Father's Age:
1.5	Mother's Age:
1.6	Address:
1.7	Your residential area: Urban or Rural

### **Part-2: Socio-Demographic Information**

<b>QN</b>	<b>Questions</b>	<b>Responses</b>	<b>Code</b>
2.1	Gender?	Male	01
		Female	02
2.2	Have you got cousin marriage?	Yes	01
		No	02
2.3	What was your age during birth of this child?	<18 year	01
		18-26 years	02
		27-35 years	03
		> 35 years	04
2.4	Mother's Educational level	No formal education	01
		Primary	02
		Secondary	03
		Higher secondary	04

		Bachelor degree or Other Higher degree	05
2.5	Father's Educational level	No formal education	01
		Primary	02
		Secondary	03
		Higher secondary	04
		Bachelor degree or Other Higher degree	05
2.6	Mother's occupation		01
2.7	Father's occupation		01
2.8	Number of child:		01
2.9	If there is any disability present	Yes or No	01
2.10	Birth history	Premature(less than 38 weeks)	01
		Term(38-42 weeks)	02
		Post-term (more than 42weeks)	03
2.11	How long your labour period was exist?	Prolonged labour(> 12hr	01
		Short labour (2-3 hr)	02
		Sudden birth(few mins)	03
2.12	Before birth do you have any	Jaundice	01
		Anaemia	02
		High Blood pressure	03
		Fall history	04
2.13	After birth child have any	Birth injury	01
		Birth asphyxia	02



2.14	How much time take the baby to cry	1-2 min	01
		3-5 min	02
		More than 5 min	03
2.15	After birth have the child got any diseases?	Jaundice	01
		Pneumonia	02
		Epilepsy	03
		Dehydration	04
		Seizure	05
		Not at all	06

Gross motor functional classification system (GMFCS):

LEVEL I : Walks without limitations

LEVEL II : Walks with limitations

LEVEL III : Walks using a Hand-Held Mobility Device

LEVEL IV : Self-Mobility with limitation; May Use Powered Mobility

LEVEL V : Transported in a Manual Wheelchair

**SF- English**

**1. In general, would you say your health is:**

---

Excellent



Very good



Good



Fair



Poor



**2. Compared to one year ago, how would you rate your health in general now?**

---

Much better  
now than one  
year ago



Somewhat  
Better now than  
one  
year ago



About the  
same as  
one year ago



Somewhat  
worse  
now than one  
year ago



Much worse  
now than one  
year ago



**3 The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?**

	Yes, limited a lot	Yes, limited a little	No, not limited at all
	▼	▼	▼
Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lifting or carrying groceries	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Climbing several flights of stairs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Climbing one flight of stairs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Bending, kneeling, or stooping	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Walking more than a kilometre	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Walking several hundred metres	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Walking one hundred metres	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Bathing or dressing yourself	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**4. During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your physical health?**

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
	▼	▼	▼	▼	▼
a. Cut down on the amount of time you spent on work or other activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Accomplished less than you would like	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Were limited in the kind of work or other activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Had difficulty performing the work or other activities (for example, it took extra effort)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**5. During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?**

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
	▼	▼	▼	▼	▼
a. Cut down on the amount of time you spent on work or other activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Accomplished less than you would like	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Did work or other activities less carefully than usual	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**6. During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours, or groups?**

Not at all	Slightly	Moderately	Quite a bit	Extremely
▼	▼	▼	▼	▼
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**7. How much bodily pain have you had during the past 4 weeks?**

None	Very mild	Mild	Moderate	Severe	Very severe
▼	▼	▼	▼	▼	▼
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**8. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?**

Not at all	Slightly	Moderately	Quite a bit	Extremely
▼	▼	▼	▼	▼
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**9. These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks...**

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
	▼	▼	▼	▼	▼
Did you feel full of life?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Have you been very nervous?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Have you felt so down in the dumps that nothing could cheer you up?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Have you felt calm and peaceful?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Did you have a lot of energy?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Have you felt downhearted and depressed?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Did you feel worn out?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Walking several hundred metres	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Have you been happy?

Did you feel tired?

**10. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?**

All of the time	Most of the time	Some of the time	A little of the time	None of the time
▼ <input type="checkbox"/>	▼ <input type="checkbox"/>	▼ <input type="checkbox"/>	▼ <input type="checkbox"/>	▼ <input type="checkbox"/>

**11. How TRUE or FALSE is each of the following statements for you?**

	Definitely True	Mostly true	Don't know	Mostly false	Definitely False
	▼	▼	▼	▼	▼
a. I seem to get sick a little easier than other people	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. I am as healthy as anybody I know	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. I expect my health to get worse	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. My health is excellent	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## প্রশ্নাবলী- বাংলা

শিরোনাম : “সেরিব্রাল পালসি শিশুদের সঙ্গে মায়ের জীবন ব্যবস্থা” ।

অংশ ১ : রোগীর সনাক্তকারী	
১.১	বাচ্চার কোড:
১.২	সাক্ষাতকার গ্রহন তারিখ :
১.৩	বাচ্চার বয়স :
১.৪	বাচ্চার বাবার বয়স:
১.৫	বাচ্চার মায়ের বয়স:
১.৬	আপনি কোথায় বাস করেন:
১.৭	আপনার আবাসিক এলাকা :গ্রাম / শহর

অংশ ২ : সামাজিক ও জনসংখ্যাভিত্তিক তথ্যবলী

প্রশ্ন নং	প্রশ্ন	উত্তর	কোড
২.১	বাচ্চার লিঙ্গ ?	ছেলে	০১
		মেয়ে	০২
২.২	আপনার কি চাচাতো ,মামাতো, খালাতো ,ফুফাতো,ভাই এর মধ্যে বিয়ে হয়েছে?	হ্যাঁ	০১
		না	০২
২.৩	এই বাচ্চা জন্মের সময় আপনার বয়স কত ছিল?	১৮-র নিচে	০১
		১৮-২৬ বছর	০২
		২৭-৩৫ বছর	০৩
		৩৫-র উপরে	০৪
২.৪	মায়ের শিক্ষাগত যোগ্যতা-	কোন প্রাতিষ্ঠানিক শিক্ষা নাই	০১



		প্রাইমারি	০২
		মাধ্যমিক শিক্ষা	০৩
		উচ্চ মাধ্যমিক শিক্ষা	০৪
		ডিগ্রী /স্নাতকোত্তর/আরো উপরে	০৫
২.৫	বাবার শিক্ষাগত যোগ্যতা-	কোন প্রাতিষ্ঠানিক শিক্ষা নাই	০১
		প্রাইমারি	০২
		উচ্চ মাধ্যমিক শিক্ষা	০৩
		মাধ্যমিক শিক্ষা	০৪
		ডিগ্রী /স্নাতকোত্তর/আরো উপরে	০৪
২.৬	মায়ের পেশা কি?		০১
২.৭	বাবার পেশা কি?		০১
২.৮	সন্তানের সংখ্যা		০১
২.৯	তাদের মধ্যে কেউ কি প্রতিবন্ধী আছে?	হ্যাঁ,না	০২
২.১০	আপনার বাচ্চা কোন সময় হয়ে ছিল?	সময়ের পূর্বে ( ৩৮ সপ্তাহের কম সময়ে )	০১
		যথাসময়ে ( ৩৮ - ৪২ সপ্তাহ )	০২

		সময়ের পরে (৪২ সপ্তাহের অধিক সময়ে )	০৩
২.১১	আপনার সন্তানের জন্ম ধরন কেমন ছিল?	প্রসব বেদনা অনেকে $< 12$ ঘণ্টা	০১
		যথাসময়ে ( ২-৩ ঘণ্টা )	০২
		হঠাৎ করে (অল্প সময়ের মধ্যে )	০৩
২.১২	জন্মের পূর্বে আপনার কি কোন অসুখ করেছিল?	জন্ডিস	০১
		অ্যানিমিয়া	০২
		উচ্চরক্ত চাপ	০৩
		পড়ে যাওয়া ইতিহাস	০৪
২.১৩	জন্মের পর বাচ্চা কি কোন আঘাত পেয়েছিল?	জন্মগত আঘাত	০১
		জন্মগত শ্বাসকষ্ট	০২
		কোনটি নয়	০৩
২.১৪	কত সময় পরে বাচ্চা কান্না করেছিল?	১-২ মিনিট	০১
		৩- ৫ মিনিট	০২
		৫ মিনিটের অধিক	০৩
		সাথে সাথে	০৪
২.১৫	শিশু জন্মের পর শিশুর কি কোন রোগে আক্রান্ত হয়েছিল ?	জন্ডিস	০১
		নিউমোনিয়া	০২

		মৃগীরোগ	০৩
		পানি শূন্যতা	০৪
		কোনটি নয়	০৫

## SF-36 প্রশ্নাবলী

### সাধারণ স্বাস্থ্য:

১. সাধারণভাবে, আপনি বলতে হবে আপনার স্বাস্থ্য হল :

১. চমৎকার      ২. খুব ভালো      ৩. ভাল      ৪. মুটামুটি      ৫. খারাপ

২. সাধারণভাবে গত এক বছর আগে তুলনায় আপনার স্বাস্থ্য বর্তমানে কেমন ?

১	২	৩	৪	৫
গত ভালো এক বছরেরও তুলনায় এখন অনেক ভালো।	গত ভালো এক বছরেরও তুলনায় এখন খানিকটা ভালো।	প্রায় গত বছরের মতই।	গত বছরেরও তুলনায় এখন কিছুটা খারাপ।	গত বছরেরও তুলনায় এখন বেশী খারাপ।

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৩. নিম্নে লিখিত প্রশ্নগুলি আপনি একটি দিনে কাজকর্মগুলি করে থাকতে পারেন সেই সম্পর্কিত। আপনার স্বাস্থ্য কি এখন আপনার এই সমস্ত কর্ম সম্পাদনে অন্তরায় হয়ে দাঁড়িয়েছে? যদি হ্যাঁ হয়, তবে কতখানি যেমন, চলমান ভারী বস্তু উদ্ধরণ, শ্রমসাধ্য খেলায় অংশ হিসেবে সবল কার্যক্রম?

	হ্যাঁ অনেকখানি অন্তরায় হয়ে দাঁড়িয়েছে	হ্যাঁ অল্পস্বল্প অন্তরায় হয়ে দাঁড়িয়েছে	না,একেবারে অন্তরায় হয় নি
a.অতিমাএায় পরিশ্রম সাধ্য কার্যবলি যেমন ভারী জিনিস তোলা , কষ্ট সাধ্য খেলাধূলা অংশগ্রন করা	▼ <input type="checkbox"/>	▼ <input type="checkbox"/>	▼ <input type="checkbox"/>
b.অপেক্ষাকৃত কম পরিশ্রম সাধ্য কার্যবলি , যেমন টেবিল সরানো, বাগান কাজ করা , সাইকেল চালানো	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c.চাল-ডাল ইত্যাদি শুকনো বাজার জিনিস তোলা বা বহন করা	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d.কয়েক তলা সিঁড়ি বেয়ে ওটা	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e.এক তলা সিঁড়ি বেয়ে ওটা	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. ঝাঁকা, হাঁটু গেড়ে বসা , নীচু হওয়া	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g.এক কিলোমিটারের বেশী হাঁটা	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h.কয়েকশো	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

i.একশো মিটার হাঁটা

৪. গত চার সপ্তাহে, আপনার শারীরিক অবস্থা কারনে , কতবার আপনার দৈনন্দিন কার্যক্রম নিম্নলিখিত সমস্যার গুলি মধ্যে কোনটি দেখা দিয়েছিল ?

	সব সময়	বেশীরভাগ সময়	মাঝে মাঝে	খুবই সময়	কম কখনই নয়
আপনার কর্ম ক্ষেত্র এবং অন্যান্য কাজে থেকে কম সময় দিতে পেরেছেন	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
আপনি যতটা চেষ্টা করেছিলেন তার থেকে কম কর্ম সম্পাদন করতে পেরেছেন	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
আপনার কৃত কর্ম কাণ্ডে মধ্যে আপনার কাজের গুণী সীমাবদ্ধ ছিল	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
আপনার কাজ করতে গিয়ে অসুবিধা হয়েছে	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

৫. গত চার সপ্তাহে, আপনি আপনার মানসিক অবস্থা কাজ বা অন্যান্য নিয়মিত দৈনন্দিন কার্যক্রম যেমন সঙ্গে নিম্নলিখিত সমস্যার কোনো ছিল ?

	সব সময়	বেশীরভাগ সময়	মাঝে মাঝে	খুবই কমসময়	কখনই নয়
আপনার কর্ম ক্ষেত্র এবং অন্যান্য কাজে থেকে কম সময় দিতে পেরেছেন	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
আপনি যতটা চেয়েছিলেন তার থেকে কম কর্ম সম্পাদন করতে পেরেছেন	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
আপনার কৃত কর্ম কাণ্ডে মধ্যে অনেক কম খেয়াল করতে পেরেছি	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

৬. গত চার সপ্তাহে আপনার পরিবার, বন্ধুবান্ধব, প্রতিবেশী সঙ্গে সামাজিক ক্রিয়াকর্ম, আপনার শারীরিক অবস্থা বা মানসিক সমস্যাগুলি, কতখানি বাধা সৃষ্টি করেছে ?

একেবারে না	সামান্য রকম	মাঝামাঝি রকম	বেশ অনেকখানি	অত্যন্তবেশী রকম
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

৭. গত চার সপ্তাহে আপনি কতখানি শারীরিক যন্ত্রণা ভোগ করেছেন ?

একেবারে না	সামান্য রকম	মাঝামাঝি রকম	বেশ অনেকখানি	অত্যন্ত
▼ □	▼ □	▼ □	▼ □	▼ □

৮. গত চার সপ্তাহে আপনি কতখানি শারীরিক ব্যথাবেদনা আপনার ( ঘরে ও বাইরের ) কাজকর্ম কতখানি বাধা সৃষ্টি ভোগ করেছেন?

একেবারে না	সামান্য রকম	মাঝামাঝি রকম	বেশ অনেকখানি	অত্যন্ত
▼ □	▼ □	▼ □	▼ □	▼ □

৯. গত চার সপ্তাহে, আপনার শারীরিক অবস্থা কিরকম কেটেছে সেই সম্পর্কিত। যে রকম কেটেছে সেই সম্পর্কিত প্রশ্ন উত্তর দিন।

	সব সময়	বেশীরভাগ সময়	মাঝে মাঝে	খুবইকম সময়	কখনই নয়
আপনি কি খুব প্রানবন্ত বোধ করছিলেন	▼ □	▼ □	▼ □	▼ □	▼ □
আপনি কি খুব স্নায়ুবিধ ভাবে দুর্বল হয়ে পড়ছিলেন ?	□	□	□	□	□



আপনি কি মানসিক অবসাদ গ্রস্ত হয়ে পরেছিলেন	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
আপনি কি সিদ্ধ ও শান্ত ছিলেন?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
আপনার কি প্রচুর প্রাণশক্তি ছিল?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
আপনি কি মানসিকভাবে হতাশ ও অবসাদগ্রস্ত হয়ে পড়েছিলেন?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
আপনি কি বিদ্বস্ত বোধ করেছিলেন?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
আপনি কি আনন্দে ছিলেন?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
আপনি কি ক্লান্ত ছিলেন?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

১০। গত চার সপ্তাহে আপনি কতখানি শারীরিক অবস্থা ও মানসিক সমস্যাগুলি আপনার ক্রিয়াকর্মে বাধা সৃষ্টি করেছে ?

সব সময়	বেশীরভাগ সময়	মাঝে মাঝে	খুবইকম সময়	কখনই নয়
▼	▼	▼	▼	▼
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

১১. নিচের বিবৃতি প্রত্যেকটি আপনার ক্ষেত্রে কত দূর সত্য বা মিথ্যা ?

	অবশ্যই সত্য	বেশীরভাগ সত্য	জানি না	বেশীর ভাগই মিথ্যা	অবশ্যই মিথ্যা
আমি মনে হয় আমি যেন অন্যদের থেকে অস্কৃত হয়ে পরছি	▼	▼	▼	▼	▼
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
আমি আমার জানাশুনা যে কোন লোক মতো সুস্থবান	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
আমি স্বাস্থ্য খারাপ হবার আশঙ্কা করি	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
আমার স্বাস্থ্য খুব ভালো	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

