

# **QUALITY OF LIFE AMONG MOTHERS OF SCHOOL GOING CHILDREN WITH CEREBRAL PALSY**

**Uarda All Rifa Trina**

Bachelor of Science in Physiotherapy (B. Sc. PT)

DU Roll No. – 153

Registration No. – 6270

Session: 2013– 2014

BHPI, CRP, Savar, Dhaka



**Bangladesh Health Professions Institute (BHPI)**

Department of Physiotherapy

CRP, Savar, Dhaka-1343

Bangladesh

August' 2018

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

**QUALITY OF LIFE AMONG MOTHER OF SCHOOL GOING CHILDREN WITH CEREBRAL PALSY**

Submitted by **Uarda Ali Rifa Trina** for partial fulfillment of the requirements for the degree of Bachelor of Science in Physiotherapy (B. Sc. PT)



**Prof. Md. Obaidul Haque**  
Head of Physiotherapy Department  
Vice Principal,  
BHPI, CRP, Savar, Dhaka.



**Mohammad Anwar Hossain**  
Associate Professor, BHPI & Head  
Department of Physiotherapy  
CRP, Savar, Dhaka.



**Mohammad Habibur Rahman**  
Associate Professor  
Department of Physiotherapy  
BHPI, CRP, Savar, Dhaka.



**Md. Shofiqul Islam**  
Assistant Professor  
Department of Physiotherapy  
BHPI, CRP, Savar, Dhaka.



**Prof. Md. Obaidul Haque**  
Head of Physiotherapy Department  
Vice Principal,  
BHPI, CRP, Savar, Dhaka.

## DECLARATION

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

Signature: Uarda All Rifa Trina

Date: 3-11-18

**Uarda All Rifa Trina**

Bachelor of Science in Physiotherapy (B. Sc. PT)

DU Roll No. – 153

Registration No. – 6270

Session: 2013-2014

BHPI, CRP, Saver, Dhaka-1343

# CONTENTS

<b>Topic</b>	<b>Page No.</b>
<b>Acknowledgment</b>	<b>I</b>
<b>Acronyms</b>	<b>ii</b>
<b>List of figures</b>	<b>iii</b>
<b>List of table</b>	<b>iv</b>
<b>Abstract</b>	<b>v</b>
<b>CHAPTER I: INTRODUCTION</b>	
1.1 Background Information	1-4
1.2 Rationale	5
1.3 Research question	6
1.4 Aim	7
1.5 Objectives	7
1.6 Operational definitions	7-8
1.7 Conceptual framework	9
<b>CHAPTER II: LITERATURE REVIEW</b>	<b>10-18</b>
<b>CHAPTER III: METHODOLOGY</b>	<b>19-23</b>
3.1 Study design	19
3.2 Study Site	19
3.3 Study population	19
3.4 Sample procedure	19
3.5 Sampling size	20
3.6 Inclusion criteria	20
3.7 Exclusion criteria	21

3.8 Data collection instrument	21-22
3.9 Data collection procedure	23
3.10 Data management & analysis	23
3.11 Ethical Consideration	23
<b>CHAPTER IV: RESULTS</b>	<b>24-40</b>
<b>CHAPTER V: DISCUSSION</b>	<b>41-45</b>
<b>CHAPTER VI: CONCLUSION AND RECOMMENDATION</b>	<b>46</b>
<b>REFERENCE</b>	<b>47-56</b>
<b>APPENDIX</b>	<b>57- 73</b>

## **Acknowledgement**

All the praise must go to Almighty Allah. At first I would like to express my gratitude to my parents who provided me a lot of encouragement to complete this study. I also gratefully acknowledge the untiring and tolerant supervision and encouragement of my supervisor Professor Md. ObaidulHaque, Head of the Department of Physiotherapy, and Vice Principal of BHPI, CRP. I remain ever grateful to him for his guidance and support without which I could not have come to this stage.

I am also grateful to my honorable teacher Ehsanur Rahman, Assistant Professor, Department of Physiotherapy for his guidance. He helped me various way to conduct research properly.

Also, it's my honor to mention Mohammad Anwar Hossain, Associate Professor, BHPI and Head of the Department of Physiotherapy, CRP, Mohammad Habibur Rahman, Associate Professor, Department of Physiotherapy and Md. Shofiqul Islam, Assistant Professor Department of Physiotherapy for their good advice, support and guide to conduct this research. I again would like to pay my gratitude to him, for giving me the permission to start this study and providing me support.

I am indebted to Md. Abdullah Al Zubayer Principal of William and Marie Taylor school(WMTS) CRP-Chapain, Savar, Dhaka for providing me the opportunity to collect participant's information from William and Marie Taylor school, CRP, Savar, Dhaka, Bangladesh.

I also pay my thanks to the library Assistant Anisur Rahman who helps me to find out books for collecting literature of the study & other staff for providing resources. I would like to thank the participants of the research for giving me their valuable time. Also, I would like to state my grateful feelings towards my honourable senior Md. Ershad Ali, friends Ganesh, Arif, Ruma, Taslima and prova, for their continuous suggestions and supports. All of my gratitude is towards Allah.

## Acronyms

**BHPI** :Bangladesh Health Professions Institute

**BMRC**:Bangladesh Medical Research Council

**CP** : Cerebral Palsy

**CRP** : Centre for the Rehabilitation of the Paralysed

**HRQoL** : Health Related Quality of Life

**IRB** : Health Related Quality of Life

**SPSS** : Statistical Package for the Social Science

**WHO** : World Health Organization

**WMTS** : William and Marie Taylor School

<b>List of table</b>
----------------------

<b>List</b>	<b>Page no.</b>
1.Associaton between Mother's health component of WHOQOL-BREF	37
2.Associaton between age of mother and component of WHOQOL-BREF	38
3.Association between income component of WHOQOL-BREF	39



## List of Figures

<b>List</b>	<b>Page</b>
1.Age of mother	24
2.Age of mother	25
3.Ratio of boy and girl among cp children	26
4.Educational level of the mother	27
5.cousin marriage of the participants	28
6.injury during baby's birth	29
7.Type of injury	30
8.Type of addiction	31
9.Type of cerebral palsy children	32
10.physical health of mother	33
11.psychological health of mother	34
12.Social relationship	35
13.Environmental health of mother	36

## 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 decreases the quality of life of mother.

**Purpose:** Identify the quality of life among mothers of school going 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 65 participants of mothers with their CP children. In additionally identify the quality of life among mothers of school going children with cerebral palsy. **Results:** Data was analyzed by using SPSS version 20. Microsoft Excel Work 2013. In this study total 65 participants of mothers with cerebral palsy children. Here minimum age of the mothers was 20 years and maximum age was 42 years. Among that the mean age of the mothers was 32.92 years and SD was 4.715. Among 65 participant mothers, most of them (50.8%) was completed secondary education level. All the 65 participants, 21.5% (n=14) got marriage with their cousin and 78.5% (n=51) was not. Quality of life of mothers was detected by a questionnaire WHOQOL-BREF and there was 4 domains, from these domains the mothers physical health was 53.8%(n=35) low quality of life and psychological health was 46.2%(n=30) low quality of life and social relationship was 53.8%( n=35) low quality of life and environmental health 40%(n=26) high quality of life. **Conclusion:** It was true that QoL of mothers was not very good with CP children, 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, WHOQOL-BREF.

**Background:**

Cerebral palsy (cp) is a dynamic disorder of posture & movement due to non-progressive brain damage resulting from defect or lesion of developing brain and it is a disease of central nervous system and children with cp have many problems such as epilepsy, deficits in speech, hearing, vision, & intellectual disability (Okurowska-Zawada *et al.*, 2011). Cerebral palsy results from brain injury when a baby's development in the womb and this is called congenital cerebral palsy and 70% of children of cerebral palsy is responsible for about this birth defect and it is present from birth it may not be detected for months (Dehghan *et al.*, 2016).

In developed countries, International assessments show 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). The prevalence of cerebral palsy in Bangladesh is 3.7/1000 children (Khandaker *et al.*, 2015). In Southern Sweden there were 358 CP children, corresponding to a prevalence of 2.70 per 1000 live births. 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 is 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 school going 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. 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, wellbeing, 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 or school 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.Children with cerebral palsy (cp),most families experience is not good. Specially parents are felling hesitate, emotional stress, guilt, fear, anxiety & insecurity (Dehghan *et al.*, 2016). 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 school going cerebral palsy children in our country. Education is one of the most fundamental aspects of development for children with cerebral palsy. Public school & private school are just a few options for children with CP. This research is about that, school going children with cerebral palsy has long term disability and mothers are the primary care giver of them. 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 school going 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 school going children with cerebral palsy?



## **1.4 Aim of the study**

To identify the quality of life of mother of school going children with cerebral palsy

## **1.5 Objectives**

### **1.5.1 General objective**

To identify the quality of life of mother of school going children with cerebral palsy.

### **1.5.2 Specific objectives:**

1. To identify the socio demographic characteristics including age, sex, educational level, marriage, birth injury, type of injury, addiction of mother, type of cerebral palsy.
2. To identify WHO quality of life (WHOQoL) of mothers with cerebral Palsy school going Children
3. To identify physical, psychological, social and environmental health of the participants
4. To identify the association between WHO quality of life (WHOQoL) and economical condition of mothers with cerebral palsy school going children.
5. To find out the association between various components of WHOQOL-BREF questionnaires and socio-demographic status.

## **1.6 Operational Definitions**

### **Cerebral palsy**

Cerebral palsy (CP) is the result of brain injury or brain malformation. It is a non-progressive brain injury or disorders of movement and posture caused by abnormal development of brain or damage to motor control centers of the brain. CP is caused by when a child brain still developing – before, during, or after birth. The abnormalities of muscle control and the impairment of motor function that define CP are often accompanied by other neurological and physical abnormalities.

**School –age child**

The age at which a child may or must begin to attend school. According to the Bangladeshi law children from the age of six years go to school.

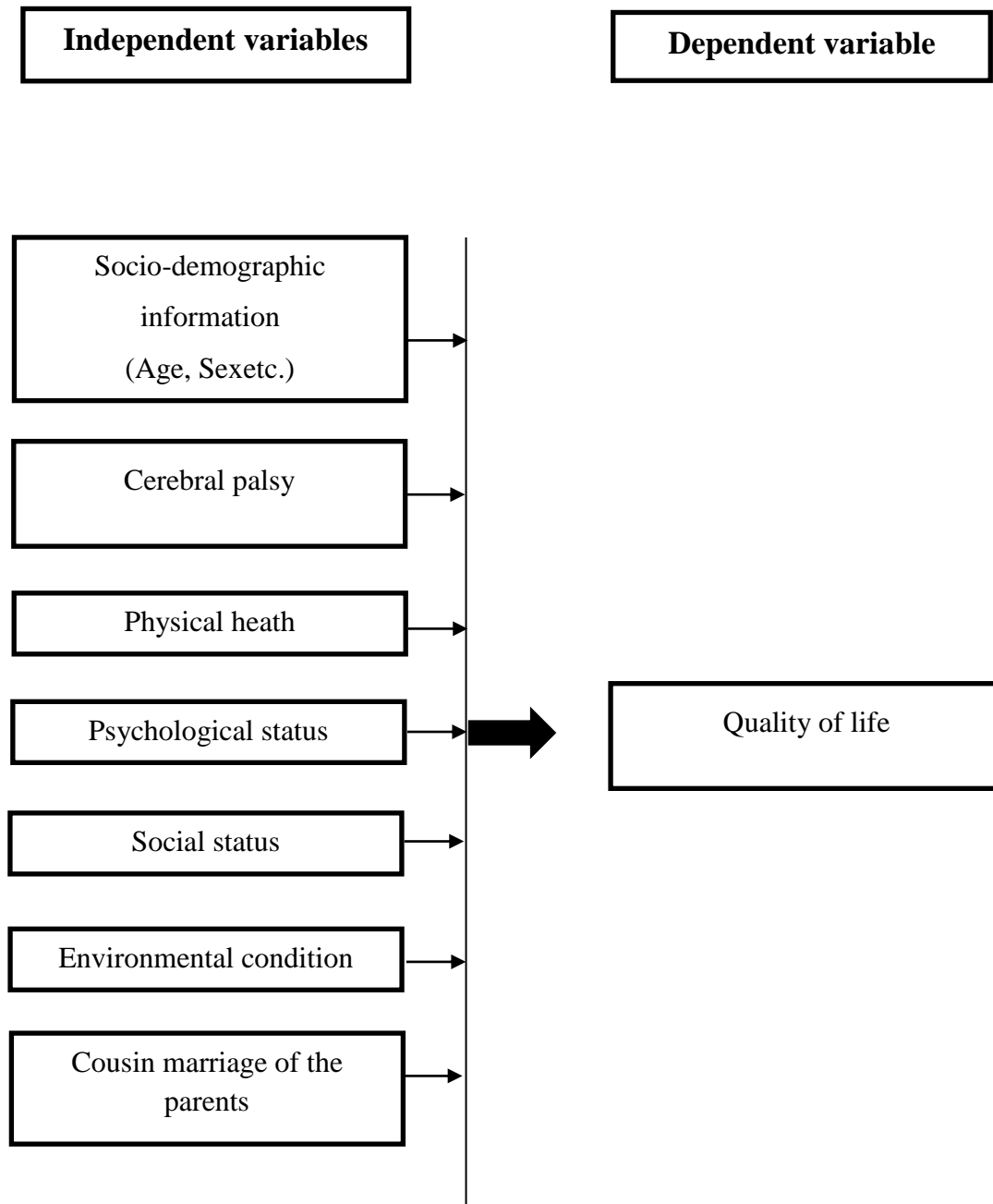
**WHO quality of life**

The general well-being of a person or society, defined in terms of health and happiness, rather than wealth. WHO quality of life (WHOQOL) is a multi-dimensional concept that includes domains related to physical, mental, emotional, environmental 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 the WHOQOL enables obtaining a quality of life profile in four domains: physical health, psychological, social relationships and environment. According to WHO quality of life is the individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals." In comparison to WHO's definitions, the Wang-Baker Faces scale defines quality of life as "life quality (in this case, physical pain) at a precise moment in time.

**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:**



The International Classification of Functioning, Disability and Health (ICF) defines that disability is an umbrella term for impairments, activity limitations and participation restrictions and a interaction between individuals with a health condition as cerebral palsy, down syndrome and depression. It also correlate with personal and environmental factors such as negative attitudes, inaccessible transportation and public buildings, and limited social supports) (WHO,2011). Cerebral palsy (CP) is no longer only a disorder however also a non-progressive group of permanent disease of the development of movement and posture that occur in the early childhood. It causes usually activity limitation of a child and disturbances of sensation, perception, cognition, communication. (Novak, 2014).

The rate of cerebral palsy is high globally. Historically found that in Australia and Europe the prevalence of cerebral palsy rate ranging from 1.5 to 2.5 per 1000 live births (CDC, 2017). A study allocated that the prevalence of ID was 10.6 per 1,000 in 1991 and at 13.6 per 1,000 in 2010 (Van Naarden Braun et al., 2015). Another recent study show significant reduction of the prevalence of Cerebral Palsy in Europe for the birth years 1980 to 2003 (Sellier et al., 2016). Total 80 percent of disabled people live in poor income countries (Gladstone, 2010). As Bangladesh is a developing country so the number of disabled people is high in our country. An epidemiological study show that children with disabilities aged 2 to 9 years in Bangladesh indicated a prevalence rate of 6.8% for all grades and types of disabilities.

A recent Bangladeshi study show that the prevalence of CP in Bangladesh is 3.7/1000 which is 1.5 more than Australia and Europe. There are about 700 children in shahjadpur. It is the sub district of shirajganj. There are 296 villages in Shahjadpur, total population of 561,076 an estimated 70,998 households and 12,117 live births per annum. In between them 859 children with severe physical impairment. Over half of those children (57 %) had never received any rehabilitative support or services. Only 21.1 % (182) of those children were attending regular school and just 0.2 % were attending special schools (Khandaker et al., 2015). A family has to faces many problems when the family has a

special child. For these parents and all family members in a family faces many challenges ( Masood et al.,2015). As cerebral palsy is a non-progressive permanent developmental disorder of movement and posture with activity limitation. So there caregiver burden is higher. Different studies shows different result on it. A study examined the level of caregiver burden of a child with cerebral palsy. They show that the most important predictors were degrees of disability of the child. When a child has functional impairment and needs long term support or is dependent on parents then the parents face more challenges when providing care for their child. A study allocated that the caregivers have poorer health condition than those who have a normal child (Brehayt et al.,2009).

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

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.

Another 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.

Diwanet 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.

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

Mothers are more likely to share their feelings rather than solve it. They need a friend rather than financial support (NurSaadahet al., 2014).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 mother's mental health (Singogo, 2015). Another study 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(Sipal& Sayin,2013)

(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.

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- 15 reports of children Quality of life(Robitail et al., 2006).

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 locomotor 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 neuroendocrinological 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 disabled 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 school going children with Cerebral palsy. For this reason a quantitative research model in the form of a cross-sectional type survey design was 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. 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 William and Marie Taylor school at Center for the Rehabilitation of the Paralyzed (CRP). This area was chosen and the patients whose were exist here meet the inclusion and exclusion criteria of the study.

### **3.3 Study population**

The study populations were cerebral palsy school going children& their mothers, who came at William and Marie Taylor school to receive education and 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 William merry school at CRP.

### 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,

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

$$p = 0.37 \text{ (Murthy et al., 2014)}$$

$$q = 1 - p$$

$$d = 0.05$$

Calculating sample was 356, but due to time limitation and availability of sample, data was not collected from 65 sample.

### 3.6 Inclusion criteria of mothers

1. Who had at least one CP children.
2. Who received treatment for her children from CRP paediatric unit.
3. Who were teaching their children in school at CRP.
4. No age limitation.
5. Who were full time career of her children.
6. Who were voluntarily agreed to participate in the study. Inclusion criteria of mothers were composed of having a child with CP, living with the child and their child going to school (Yilmaz et al., 2013).

### Inclusion criteria of CP children

1. Age range between 6 to 18 years.
2. Both male & female.
3. Any type of CP, whose diagnosis was confirm by physician. Mothers with CP children were 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 18 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 WHOQOL-BREF & socio-economic informative questionnaire were used for data collection.

### **Measurement tools**

A socio-demographical informative questionnaire was developed by researcher to collect data. A preformedpretested questionnaire/tool named the WHOQOL-BREF questionnaire which measures Quality of Life (QOL) across four domains.

## **WHO-BREF**

The WHOQOL-BREF instrument comprises 26 items, which measure the following broad domains: physical health, psychological health, social relationships, and environment. The WHOQOL-BREF is a shorter version of the original instrument that may be more convenient for use in large research studies or clinical trial.

### **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 WHOQOL-BREF**

WHOQOL-BREF 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. Quality of life of mothers 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-zawada et al., 2011).



### **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, type of injury and type of cerebral palsy children, along with questionnaire of WHOQOL-BREF. Data was collected from patient present in William and Marie Taylor school of CRP; Savar and researcher collected data from 28 July 2018 to 28 August 2018.

### **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 analyzed through Statistical package of social science (SPSS) version 20 and data was leveled in Microsoft Excel worksheet and arranged in results. Then data was analyzed through descriptive statistics and descriptive statistics was used to fulfill research objectives.

### **3.11 Ethical considerations**

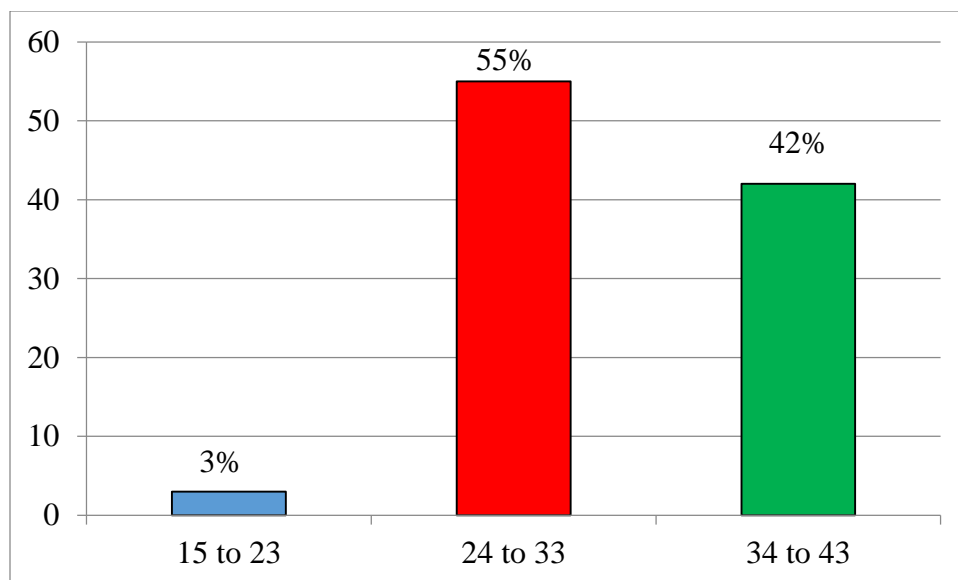
The proposal was submitted to the Institutional Review Board (IRB) of Bangladesh Health Professions Institute (BHPI) & approval was obtained from the board. The whole process of this research project was done by following the Bangladesh Medical Research Council (BMRC) guidelines and World Health Organization (WHO) Research guidelines. Verbal and written informed consent was taken from every participants. And ensure every participants 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. 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, quality life of mother was assessed by using WHOQOL-BREF questionnaires among the 65 participant mothers of school going children with cerebral palsy. This study found the socio-demographic information of the participants.

#### 4. Socio-demographic information

##### 4.1 Age of Mother

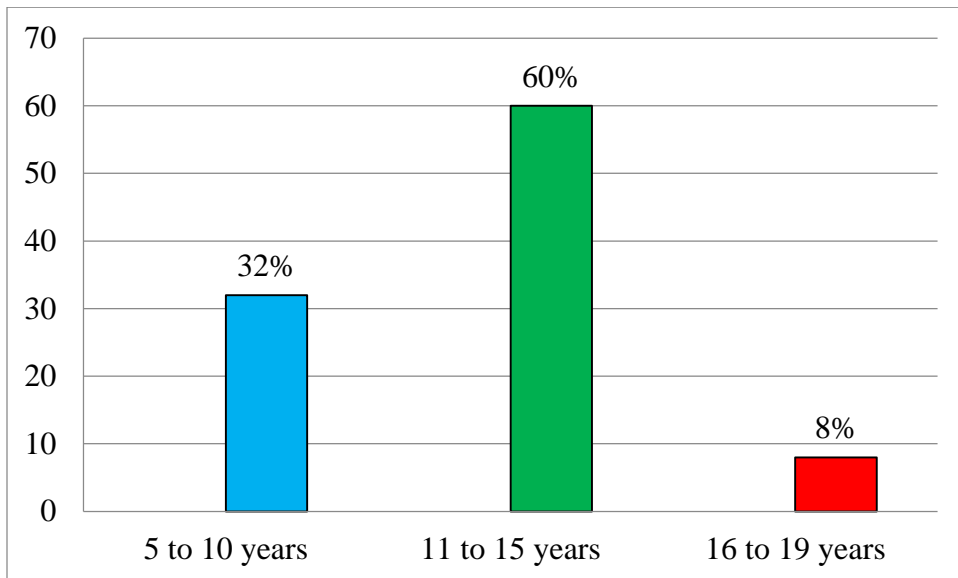
Among the 65 participants, about 3%(n=2) participants were between 15-23 age and about 55% (n=36) participants were between 24 to 33 age and 42%(n=27) participants were between 34 to 43 age.(Figure-1)



**Figure (1):Mother ageof the participants**

#### 4.2 Age of children

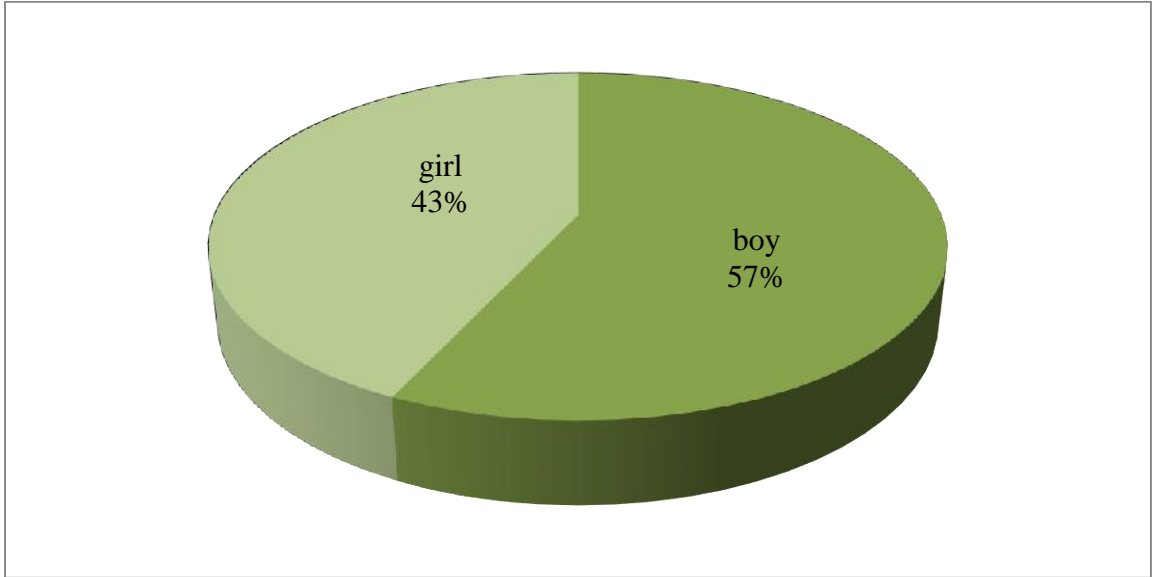
Among the 65 participants, about 32 % (n=21) participants children age were between 5-10 years and about 60% (n=39) participants children age were between 11 to 15 years and 8% (n=5) participants were between 16 to 19 age.(Figure-2)



**Figure (2): Age of children**

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

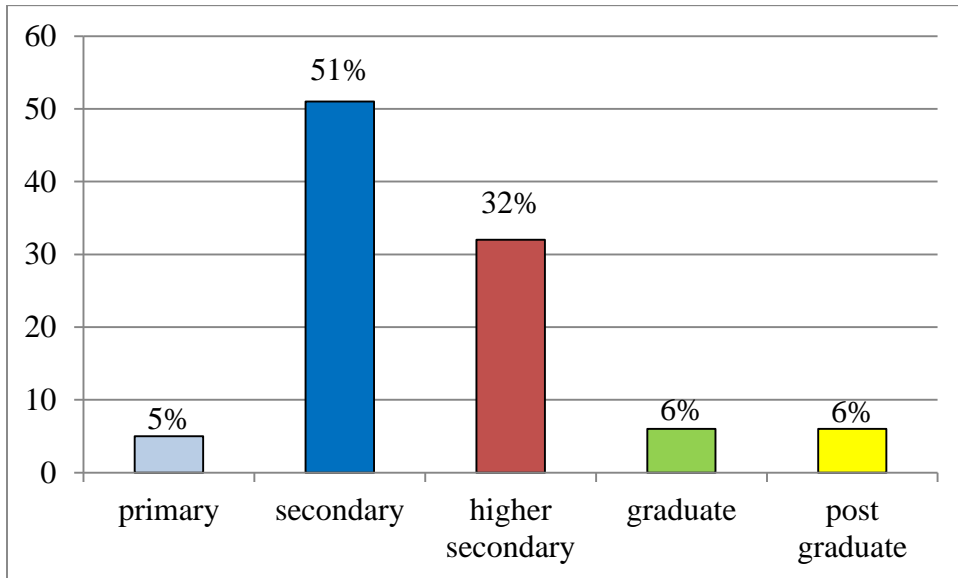
Among the 65 participants, 57 % (n=37) children were boy and 43% (n=28) were girl.  
(Figure-3)



**Figure(3): Gender ratio between Boy and Girl.**

#### 4.4 Education level of the mothers

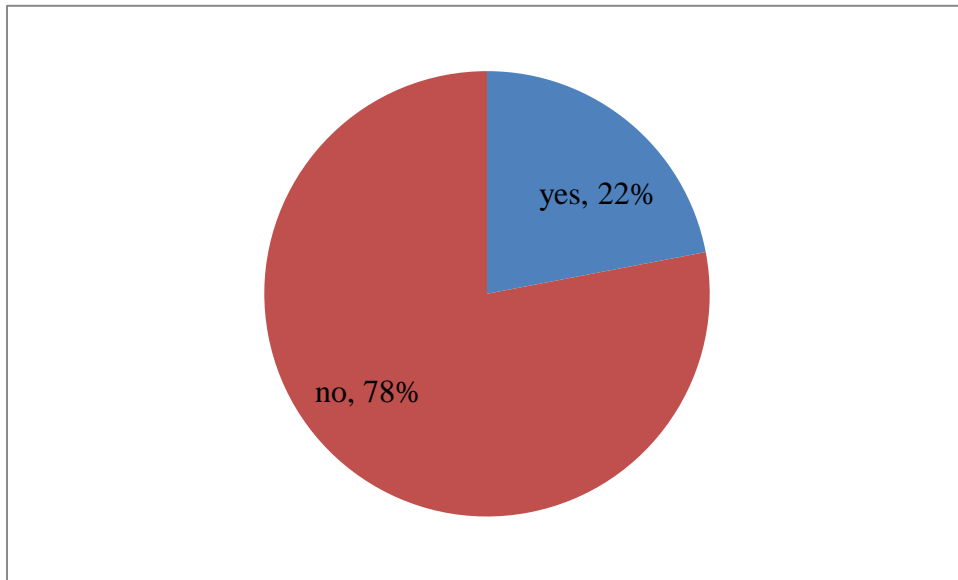
Out of the 65 participants mother, education status showed that 5% (n=3) mothers were completed primary education, 51% (n=33) completed secondary education, 32% (n=21) completed Higher Secondary education, 6% (n=4) completed Bachelor degree, and 6%(n=4) completed post -graduation education.(Figure-4)



**Figure-4: Mother educational level**

#### 4.5 : Cousin marriage of the participants

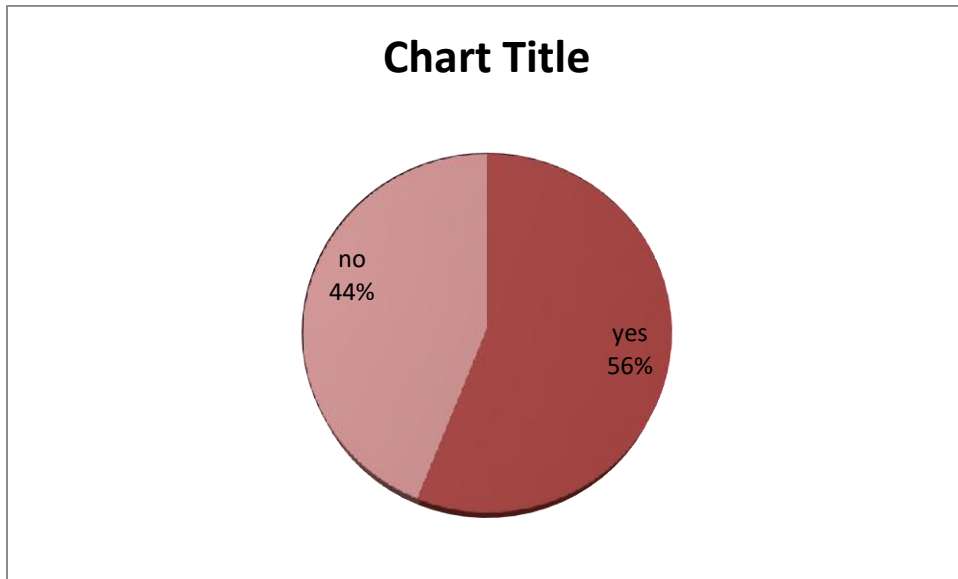
Among 65 the participant 21.5% (n=14) was got cousin marriage and 78.5% (n=51) were not cousin marriage.(Figure-5)



**Figure-5: Cousin marriage of the participants**

#### 4.6 Injury during baby's birth

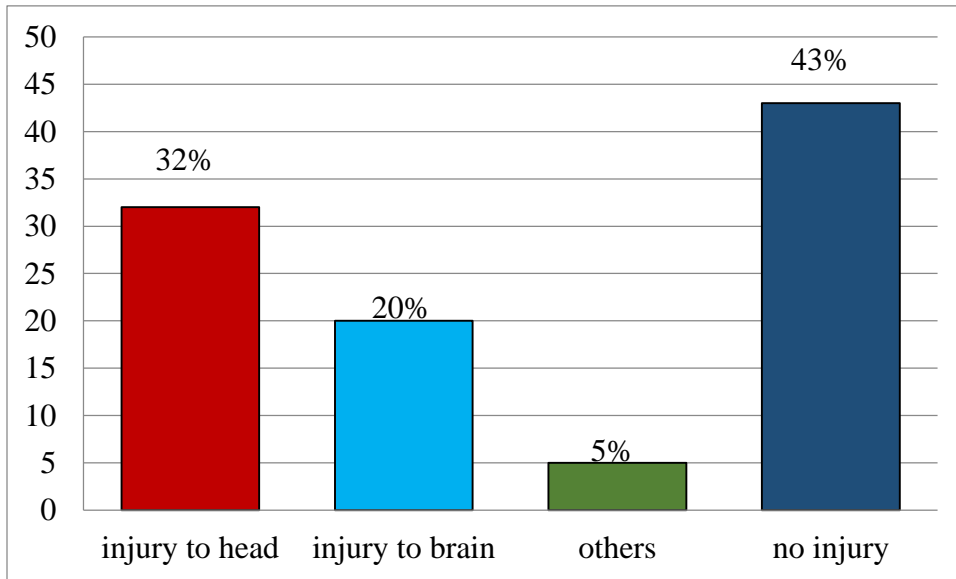
Out of 65 participants, 56% (n=37) participants had present birth injury and 44 % ( n=28) had not present. (Figure-6)



. **Figure(6): Injury during baby's birth**

#### 4.7 Type of injury

Out of 65 participants, 32% (n=21) participants had present injury to head, 20% (n=13) had injury to brain, others injury 5% (n=3) and 43% (n=28) had not present. (figure-7)

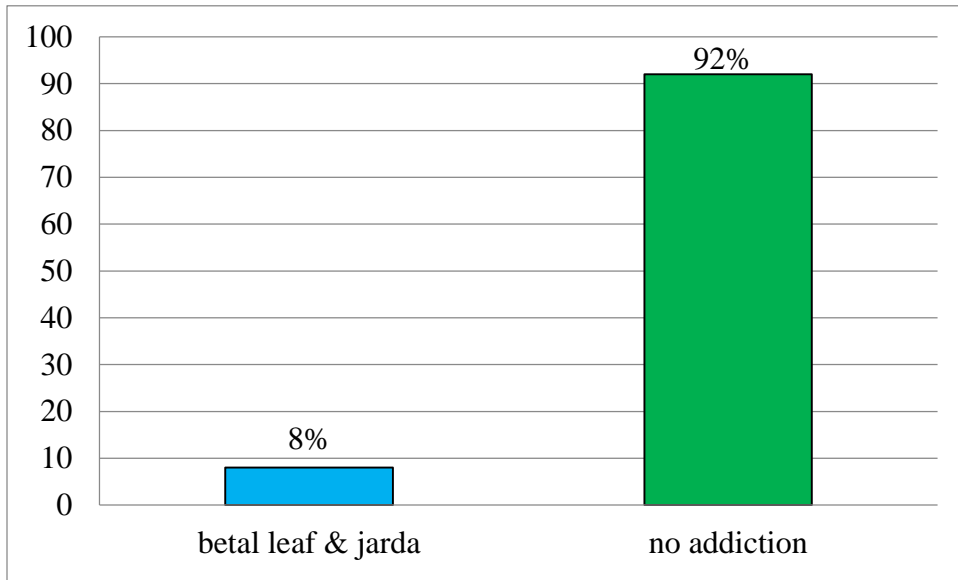


**Figure-7: Type of injury**



#### 4.8 Type of Addiction of Mother

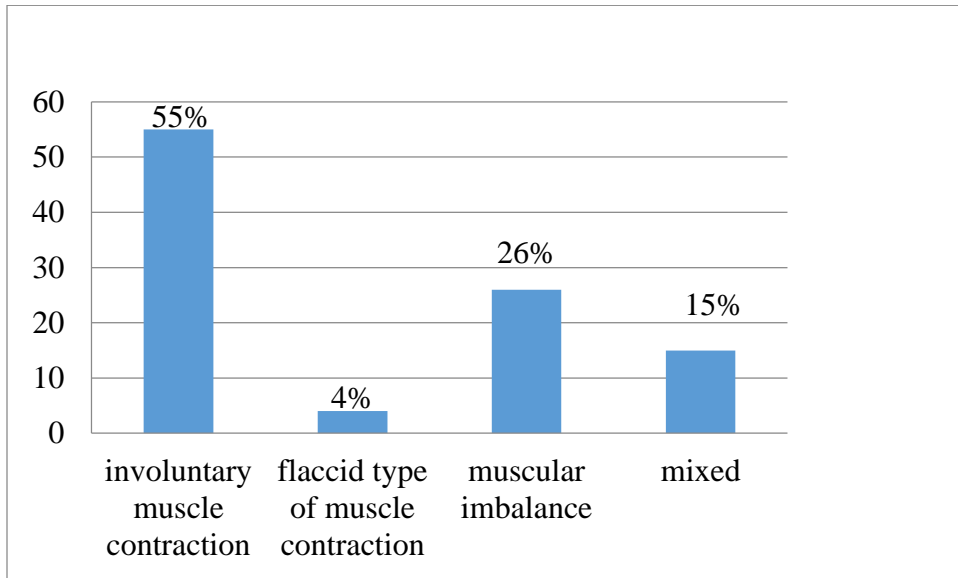
All 65 the participant 7.7% (n=5) was addicted by betal leaf & jarda and 92.3% (n=60) was not addicted.(Figure-8)



**Figure-8:**Type of addiction of mothers.

#### 4.9 Type of cerebral palsy child

The figure showing that type of cerebral palsy children in involuntary muscle contraction was 55.4% (n=36), flaccid type of muscle contraction was 3.1%(n=2), muscular imbalance 26.2% (n=17) and mixed was 15.4% (n=10) among 65 participants. (Figure-9)

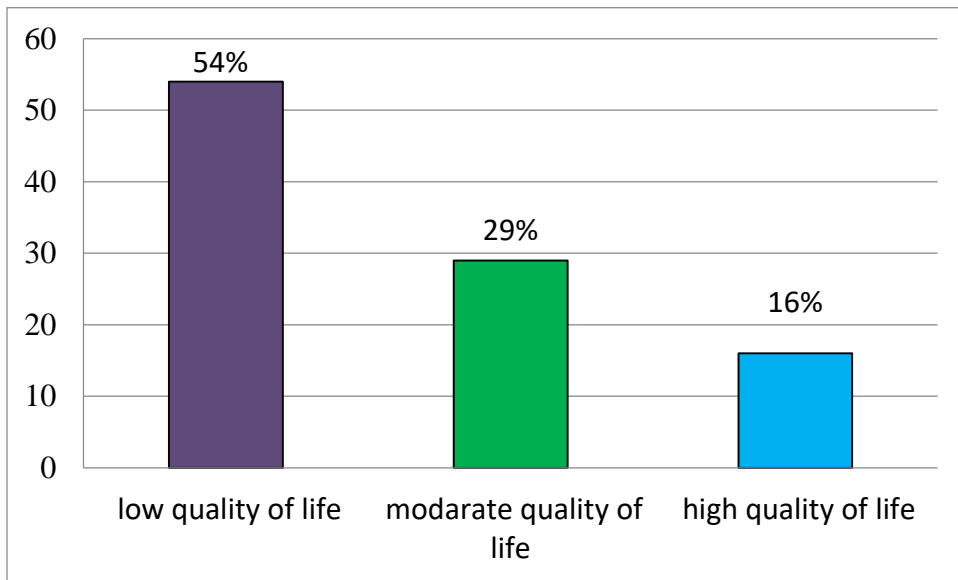


**Figure-9: Type of cerebral palsy child**

## WHOQOL-BREF scoring among the participants mother

### 4.10 Physical Health of Mother

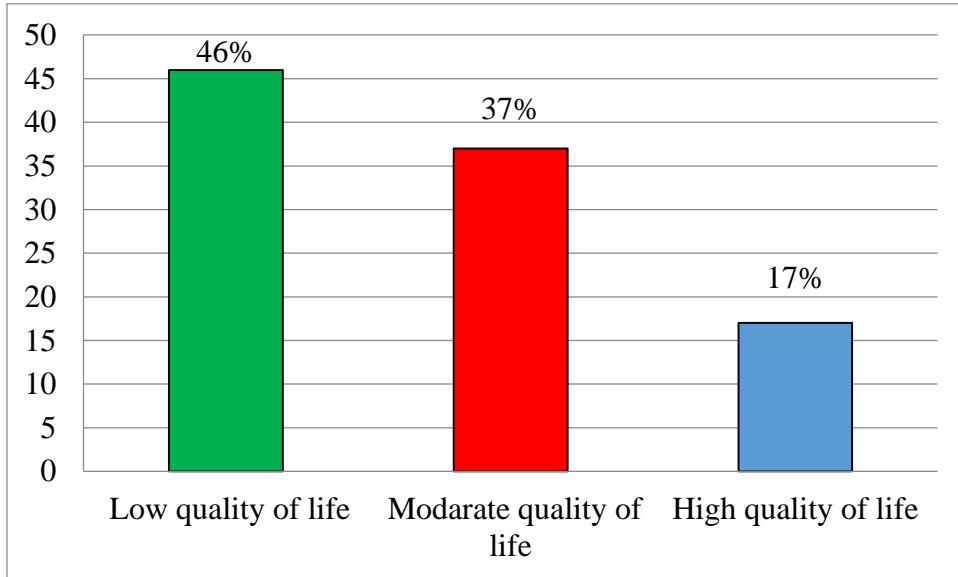
The figure showing that 54% mother's physical health is low quality, 29% mother's physical health is moderate quality and 16% mother's physical health is high quality of life. (Figure-10)



**Figure(10): Physical health**

#### 4.11 Psychological health of mother

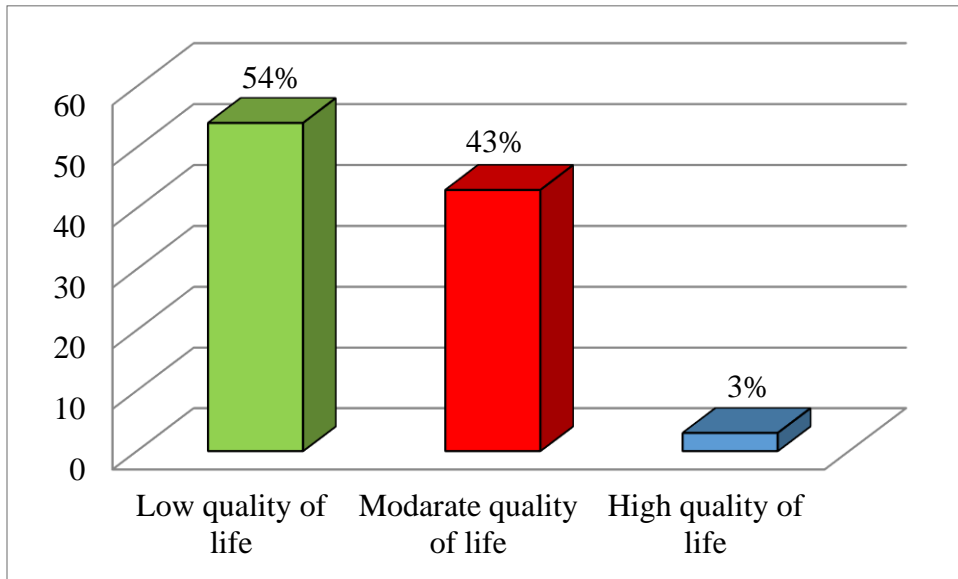
The figure shows that 46% mother's psychology is low quality of life, 37% mother's life is moderate quality of life and 17% are high quality of life. (Figure-11)



**Figure – 11: Psychological health.**

#### 4.12 social relationship

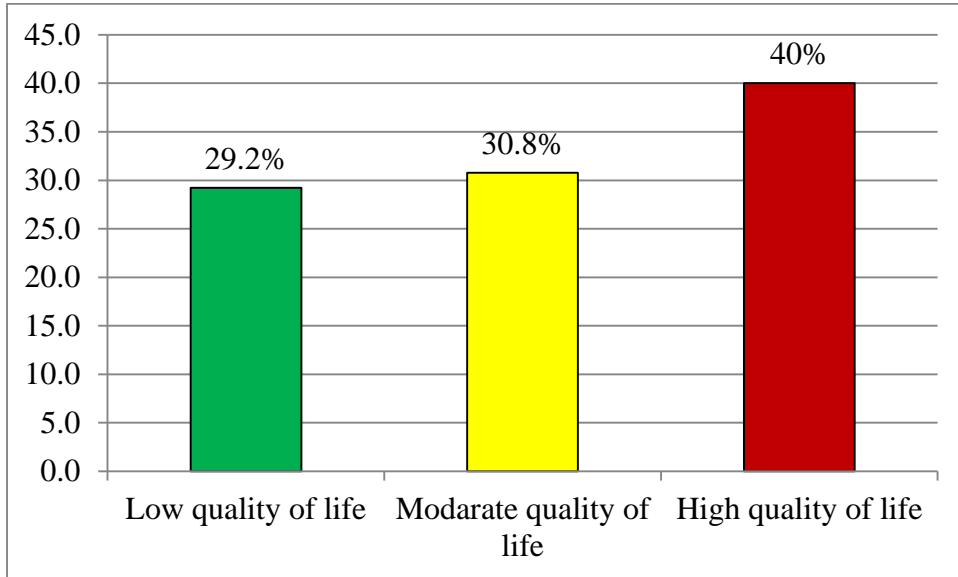
All 65 participant 54% (n=35) had low quality social relationship, 43%(n=28) had mild to moderate quality of life and 3% (n=2) high quality of life.



**Figure(12):social relationship**

#### 4.13 Environmental health of mother.

Among 65 participants 29.2% (n=19) had low quality environmental health, 30.8% (n=20) had mild to moderate quality of life and 40% (n=26) high quality of life.



**Figure :13 – Environmental Health**

Table 1 : Association between Mother's educational qualification and component of WHOQOL-BREF (physical health, psychological health, social relationship and environmental health)

<b>Mother's Educational Qualification</b>	<b>Component of WHOQOL-BREF</b>	<b>Chi-Square Value</b>	<b>P-Value</b>	<b>Significance</b>
<ul style="list-style-type: none"> <li>• Uneducated</li> <li>• Primary</li> <li>• Secondary</li> <li>• Higher-secondary</li> <li>• Graduate</li> <li>• Post graduate</li> <li>• Others</li> </ul>	Physical Health	16.875	0.03	Significant
	Psychological Health	19.644	0.012	Significant
	Social Relationship	3.331	0.912	Not-significant
	Environmental Health	6.604	0.580	Not-significant

From Table-1: The association found between mothers educational qualification and Physical health which was statistically significant ( $P < .031$ ). Association found between Mother's educational qualification and Psychological health which was statistically significant ( $P < .012$ ).

No association found between mother's educational qualification and social relationship which was not statistically significant ( $P > .912$ ). No association found between mother's educational qualification and environmental health which was not statistically significant ( $P > .580$ ).

So, it has found that mother's educational qualification moderately affects quality of life among mothers of school going CP child.

Table-2: Association between Age of Mother and component of WHOQOL-BREF (physical health, psychological health, social relationship and environmental health)

Age of Mother (Years)	Component of WHOQOL-BREF	Chi-square Value	P-value	Significance
15-23	Physical Health	3.397	0.494	Not-significant
	Psychological Health	3.544	0.471	Not-significant
24-33	Social Relationship	4.050	0.399	Not-Significant
	Environmental Health	3.930	0.416	Not-significant

In Table-2, No association found between age of mother and Physical health which was not statistically significant ( $P > .494$ ). No association found between age of mother and Psychological Health which was not statistically significant ( $P > .471$ ). No association found between age of mother and social relationship which was not statistically significant ( $P > .399$ ). No association found between age of mother and environmental health which was not statistically significant ( $P > .416$ ).

So, it has found that age of mother does not affect the quality of life among mother of school going CP child.



Table-3: Association between Income (month/tk) and component of WHOQOL-BREF (physical health, psychological health, social relationship and environmental health)

Income (Month/tk)	Component of WHOQOL-BREF	Chi-square Value	P-Value	Significance
(3000-5000)	Physical Health	74.152	0.000	Significant
(5000-10000)	Psychological Health	60.347	0.000	Significant
(>10000)	Social Relationship	4.075	0.667	Not-significant
Others	Environmental Health	31.265	0.000	Significant

From Table-3: The association found between income and Physical health which was statistically significant ( $P < .000$ ). Association found between income and Psychological health which was statistically significant ( $P < .000$ ). Association found between income and Environmental health which was statistically significant ( $P < .000$ ).

No association found between income and social relationship which was not statistically significant ( $P > .667$ ).

So, it has shown that Family income affects greatly the quality of life among mother of school going CP child.

The WHOQOL-BREF questionnaire is easy to apply to participants and it doesn't require a lot of time to answer the questions and process the data. And it is easy to evaluate individual patients. The WHOQOL-BREF consists of four domains, which are the sums of the questions in their section. This data was also analysed by using SPSS version 20.

From 65 participants the minimum & maximum percentage of physical health was The figure showing that 17% mother's physical health is very good and 29% mother's physical health is moderate quality of life and 53% mother's health is low quality of life. It means the physical quality of mother is poor. The figure shows that 17% mother's psychology is very good and 37% are mild to moderate and 46% mother's psychological health is low quality. It means the psychological quality of mother is poor. All 65 participants 53.8% (n=35) had low quality social relationship, 43.1% (n=28) had mild to moderate quality of life and 3.1% (n=2) high quality of life. It means the social quality of mother is poor. The figure showing that 40% mother's environmental health is very good and 31% mother's environmental health is moderate quality of life and 29% mother's environment health is low quality of life.

This discussion is based on among 65 participant's mother & their children. According to the results of the present study, most of the participant mothers age range were (14-42) 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 42 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.

In my study, Out of the 65 participants mother, education status showed that 4.6% (n=3) mothers were completed primary education, 50.8% (n=33) completed secondary education, 32.3% (n=21) completed Higher Secondary education, 6.2% (n=4) completed Bachelor degree, and 6.2% (n=4) completed post -graduation education. so, educational status is not very good. There is association between mothers educational qualification and extend she feels her life to be meaningful. Another study in Australia found that, 1.5% were completed primary level, 37.2% high school level, 22.1% trade certification and 29% university. From another study in U.S.A showed that 6.7% mothers were completed H.S.C (Hwang et al., 2011). So, less education can effect for continuing good life.

Birth injury is a common problem for developing CP children. From the study out of 65 participants, 56.9% (n=37) participants children had present birth injury and 43.1% (n=28) had not present. 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 65 participant 21.5% (n=14) was got cousin marriage and 78.5% (n=51) was not cousin marriage. The union between two people genetically related by descent from a common ancestor is called consanguineous marriage and 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%) and however the frequency varies by region, 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 upon the family members. 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. (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 and also affects mothers physical well-being, freedom and independence and financial stability (Davis et al.,2010).In my study, 54% mother's physical health is low quality, 29% mother's physical health is moderate quality and 16% mother's physical health is high quality of life out of 65 participant. So the physical health of school going cerebral palsy children mothers is low quality of life.

The quality of life in mothers of children with cerebral palsy was statistically significant poorer and mothers of children with difficulties had significantly more negative emotional conditions and more symptoms of depression because they had lack of positive feelings such as joy, pleasure, loveliness, pride and fulfillment of hope(Glinacet al.,2017).

In my study I found that 46% mother's psychology is low quality of life,37% mother's life is moderate quality of life and 17% are high quality of life.so, mothers psychological health is very poor.. 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.

In my study, 53.8% (n=35) had low quality social relationship,43.1%(n=28) had mild to moderate quality of life and 3.1% (n=2) high quality of life so,social relationship of cerebral palsy children mothers is not very good. As a result of cultural impacts in Turkey, mothers mostly take over the responsibility for disabled children and 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 and it was reported that decrease the social activities of mothers with disable children. In several studies, it has been indicated that mothers of disabled children give up other roles in society, attend less to social activities, and have less social life due to their increased responsibilities for childcare ( Ergun et al.2012).

All 65 participant 29.2% mothers of cerebral palsy children had low quality environmental health, 30.8% had mild to moderate quality of life and 40% high quality of life. So, mothers' environmental health is very good. Another study found that maternal mental health is dependent on environmental factors (Burk et al., 2012).

The study shows that the association between monthly income and physical health ( $P < .000$ ) and also association between monthly income and psychological domain ( $P < .000$ ). Comparing the data from the study, the largest differences occur in parents of children with cerebral palsy in the environment domain,  $p < 0.0068$ , and the psychological domain,  $p < 0.010$  (Okurowska –Zawada et al., 2011).

My study shows that there is association between educational status of mother and physical health ( $P < .03$ ) and also association between educational status of mother and psychology domain ( $P < .012$ ). My study shows that there is strong association between monthly income and environmental health of the participant ( $p < 0.00$ ). Another study showed that economic condition is associated strongly with the environmental domain,  $p < .0019$  (Mahani et al., 2013).

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 required for the children's disabilities but also psychological support for the mother.

### **Limitations**

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 named William and Marie Taylor school 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 school going CP children. So the results of the study was not compare with other disable children.

### **6.1 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. Maximum children had lower level of functional status and we general people sometime think that this poor functional level can affect the Qol of school going cerebral palsy children 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 social life is mild good of school going cerebral palsy children mother. 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.

### **6.2 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.



## References

Allah, E.S.A., Awady, S.E. and Hameed, H.S.A.E., (2012). Improving the care provided to Hemiplegics Cerebral Palsy Children by Their family caregivers: An Intervention study. *Journal of American Science*, 8(2):730-737.

Alsem, M.W., Ketelaar, M. and Verhoef, M., (2013). The course of health-related quality of life of preschool children with cerebral palsy. *Disability and rehabilitation*, 35(8):686-693.

Arnaud, C., Fauconnier, J., Dickinson, H.O., Beckung, E., Marcelli, M., McManus, V., Michelsen, S.I., Parkes, J., Thyen, U. and Colver, A., (2009). Participation in life situations of 8-12 year old children with cerebral palsy: cross sectional European study. *British Medical Journal*, 338:1458.

Aydin, R. and Nur, H., (2012). Family-Centered Approach in the Management of Children with Cerebral Palsy. *Turkish Journal of Physical Medicine and Rehabilitation*, 58(3):229-235.

Bayatiani, A., Pourmohammadreza, Tajrishi, M., Gangalivand, N., Mirzamani, M. and Salehi, M., (2011). The Relationship between Social Network and Quality of Life in Parents of students with Intellectual Disabilities (Persian). *Iranian Journal of Exceptional Children*, 2(11):163-174.

Bialik, G.M., Gad, M. and Givon, U., (2009). Cerebral palsy: classification and etiology, *ActaOrthopaedicaTraumatologicaTurcica Journal*, 43(2):77-80.

Bourke-Taylor, H., Pallant, J. F., Law, M. and Howie, L., (2012). Predicting mental health among mothers of school-aged children with developmental disabilities: The relative contribution of child, maternal and environmental factors. *Research in developmental disabilities*, 33(6):1732-1740.

Brown, C.R., Hilman, S. J., Richardson, A.M., Herman, J.L. and Robb, (2008). Reliability and validity of the visul gait assessment scale for children with hemiplegic cerebral palsy when used by experienced and inexperienced observers. *Gait & posture*, 27(4):648- 652.

Brehaut, J. C., Kohen, D. E., Garner, R. E., Miller, A. R., Lach, L. M., Klassen, A. F., & Rosenbaum, P. L. (2009). Health among caregivers of children with health problems: Findings from a Canadian population-based study. *American Journal of Public Health*, 99(7):1254-1262.

Centres for Disease Control and Prevention Available on: <https://www.cdc.gov/ncbddd/cp/data.html> [ Access on 14th September 2017].

Dehghan, L., Dalvand, H., Feizi, A., Samadi, S.A. and Hosseini, S.A.,( 2016). Quality of life in mothers of children with cerebral palsy: The role of children's gross motor function. *Journal of child health care*, 20(1):17-26.

Diwan, S. H., Chovatiya, and Diwan, J., (2011). "Depression and quality of life in mothers of children with cerebral palsy," *National Journal of Integrated Research in Medicine*, 2 (4):11–13.

Davis, E., Shelly, A.M.Y., Waters, E. and Davern, M., (2010). Measuring the quality of life of children with cerebral palsy: comparing the conceptual differences and psychometric properties of three instruments. *Developmental Medicine & Child Neurology*, 52(2):174- 180. 47

Davis, E.,Shelly A, Waters, E. Boyd,R. Cook,K. Davern, M.,(2010).The impact of caring for mother and father. *Child Care Health*, 36 (1):63-73.

Dayapoglu, N. and Tan, M., (2010). Quality of life in stroke patients. *Neurology India journal Impact & Description*, 58(5):697.

Dale, E. Jahoda, A. and Knott, F. (2006). Mothers' attributions following their child's diagnosis of autism spectrum disorder. *Autism*, 10:463-479.

Edwards, V., Wyatt, K., Logan, S., and Britten N., (2011). Consulting parents about the design of a randomized controlled trial of osteopathy for children with cerebral palsy. *Health Expect.* Jan; 18. doi: 10.1111.

Elkamil, A.I., Andersen, G.L., Hägglund, G., Lamvik, T., Skranes, J. and Vik, T., (2011). Prevalence of hip dislocation among children with cerebral palsy in regions with and without a surveillance programme: a cross sectional study in Sweden and Norway. *BioMed Central. Musculoskeletal Disorders*, 12(1):1.

Ergün, S. and Ertem, G., 2012. Difficulties of mothers living with mentally disabled children. *development*, 1(3):213-30.

Glenn, S., Cunningham, C., Poole, H., Reeves, D. and Weindling, M., (2009). Maternal parenting stress and its correlates in families with a young child with cerebral palsy. *Child: Care, Health and Development*, 35(1):71-78

Glinac, A., Matovic, L., Delalic, A. and Mesalic, L., (2017). Quality of Life in Mothers of Children with Cerebral Palsy. *ActaclinicaCroatica*, 56(2.):299-307.

Gorter, J.W., Ketelaar, M., Rosenbaum, P., Helders, P.J. and Palisano, R., (2009). Use of the GMFCS in infants with CP: the need for reclassification at age 2 years or older. *Developmental Medicine & Child Neurology*, 51(1):46-52.

Garel, M., Dardennes, M. and Blondel, B., (2007). Mothers' psychological distress 1 year after very preterm childbirth. Results of the epipage qualitative study. *Child: Care, Health and Development*, 33(2):137-143.

Gladstone, M. (2010). A review of the incidence and prevalence, types and aetiology of childhood cerebral palsy in resource-poor settings. *Annals of Tropical Paediatrics*, 30(3):181-196.

Hannan, J.M.A., (2007). *Medical & Pharmaceutical Statistics*. Islamia Market, Nilkhet, Dhaka: Apex Publications. Hustad, K.C., Gorton, K. and Lee, J., (2010). Classification of speech and language profile in 4years old children with cerebral palsy. *National Institute of Health Public Access Author Manuscript*, 53(6):1496-1513.

Hustad, K.C., Gorton, K. and Lee, J., (2010). Classification of speech and language profile in 4years old children with cerebral palsy. *National Institute of Health Public Access Author Manuscript*, 53(6):1496-1513.

Himpens, E., Van, D., Broeck, C., Oostra, A., Calders, P. and Vanhaesebrouck, P., (2008). Prevalence, type, distribution, and severity of cerebral palsy in relation to gestational age: a meta-analytic review. *Developmental Medicine & Child Neurology*, 50(5):334-340.

Hilari, K., Cruice, M., Sorin-Peters, R. and Worrall, L., (2016). Quality of Life in Aphasia: State of the Art. *Folia Phoniatricae et Logopaedica*, 67(3):114-118.

Habashneh, R., Khader, Y. S. and Salameh, S., (2012). Use of the Arabic version of Oral Health Impact Profile-14 to evaluate the impact of periodontal disease on oral health related quality of life among Jordanian adults. *Journal of Oral Science*, 54(1):113-120.

Hagh, R. F., Kakavand, A., Borjali, A. and Barmas, H., (2011). Resiliency and quality of life of mothers of children with mental retardation (Persian). *Journal of Health Psychology*, 1(1):177-187.

Jenkinson, C., Lloyd, H., Hadi, M., Gibbons, E. and Fitzpatrick, R., (2014). Patient reports of the outcomes of treatment: a structured review of approaches. *Health and quality of life outcomes*, 12(1):5.

Jalili, N., Goudarzi, M., Rsfayany, M., Haghgoo, H., Dalvand, H. and Marjan, F., (2013). Quality of life in mothers of children with severe cerebral palsy and factors affecting it (Persian). *Journal of Modern Rehabilitation*, 7(3):40-47.

Karande, S. and Kulkarni, S., (2009). Quality of life of parents of children with newly diagnosed specific learning disability. *Journal of Postgraduate Medicine*, 55(2):97.

Kaya, S., Unsal-Delialioglu, N. K. and Ordu-Gokkaya, (2010). "Musculo-skeletal pain, quality of life and depression in mothers of children with cerebral palsy, "Disability and Rehabilitation, 32 (20):1666–1672.

- Keller, J., Stashinko, E.E., Nagae, L.M., Lin, D.D., Bastin, A., Campbell, M.L., Levey, E., Mori, S. and Johnston, M.V., (2009). Sensory and motor deficits in children with cerebral palsy born preterm correlate with diffusion tensor imaging abnormalities in thalamocortical pathways. *Developmental medicine & Child neurology*, 51(9):697-704.
- Koohsali, M., Mirzamani, M., Karimlo, M. and Mirzamani, M., (2008). Comparing of social adjustment in mothers of educable mentally retarded daughter (Persian). *Journal of Behavioral Sciences*, 2(2):165-172.
- Kuřak, W., Sobaniec, W., Kuzia, J.S. and Bockowski, L., (2006). Neurophysiologic and neuroimaging studies of brain plasticity in children with spastic cerebral palsy. *Experimental neurology*, 198(1):4-11.
- Khandaker, G., Smithers-Sheedy, H., Islam, J., Alam, M., Jung, J., Novak, I., & Muhit, M. (2015). Bangladesh Cerebral Palsy Register (BCPR): a pilot study to develop a national cerebral palsy (CP) register with surveillance of children for CP. *BMC neurology*, 15(1):173.
- Laurvick, C.L., Msall, M.E., Silburn, S., Bower, C., Klerk, N. and Leonard, H., (2006). Physical and mental health of mothers caring for a child with Rett syndrome. *Paediatrics*, 118(4):1152-1164.
- Murthy, G.V., Mactaggart, I., Mohammad, M., Islam, J., Noe, C., Khan, A.I. and Foster, A., (2014). Assessing the prevalence of sensory and motor impairments in childhood in Bangladesh using key informants. *Archives of disease in childhood*, 99(12):1103-1108.
- Masood, A., Arshad, R., & Mazahir, S. (2015). Families of Children with Cerebral Palsy: Family Functioning Domains. *International Journal of School and Cognitive Psychology*, doi:10.4172/1234-3425.1000119
- Mugno, D., Ruta, L., D'Arrigo, V. G. and Mazzone, L., (2007). Impairment of quality of life in parents of children and adolescents with pervasive developmental disorder. *Health and Quality of Life Outcomes*, 5(22):1-9.

Mahani, M.K., Rostami, H.R. and Nejad, S.J., (2013). Investigation of quality of life determinants among mothers of children with pervasive developmental disorders in Iran. *Hong Kong Journal of Occupational Therapy*, 23(1):14-19.

Netuveli, G. and Blane, D., (2008). Quality of life in older ages. *British medical bulletin*, 85(1):113-126.

Novak, I. (2014). Evidence-based diagnosis, health care, and rehabilitation for children with cerebral palsy. *Journal of Child Neurology*, 29(8):1141-1156.

Nesterko, Y., Braehler, E., Grande, G. and Glaesmer, H., (2013). Life satisfaction and health-related quality of life in immigrants and native-born Germans: the role of immigration-related factors. *Quality of Life Research*, 22(5):1005-1013.

NurSaadaah, MA., AB, S. H., & Islam, M. R. (2014). Coping Strategies Among Mothers of Chronically Ill Children: A Case Study in Malaysia. *Journal of Social Service Research*, 40(2):160-177.

Oskoui, M., Coutinho, F., Dykeman, J., Jetté, N. and Pringsheim, T., (2013). An update on the prevalence of cerebral palsy: a systematic review and meta-analysis. *Developmental Medicine & Child Neurology*, 55(6):509-519.

Okurowska-Zawada, B., Kulak, W., Wojtkowski, J., Sienkiewicz, D. and Paszko-Patej, G., (2011). Quality of life of parents of children with cerebral palsy. *Progress in Health Sciences*, 1(1):116-124.

Ozel, S., Unsal-Delialioglu, S., Kaya, K. and Gorgulu, G., (2009). Depression in mothers of children with cerebral palsy and related factors in Turkey: a controlled study. *International Journal of Rehabilitation Research*, 32(3):199-204.

Prudente, C.O.M., Barbosa, M.A. and Porto, C.C., (2010). Relation between quality of life of mothers of children with cerebral palsy and the children's motor functioning, after ten months of rehabilitation. *Revista Latino-Americana de Enfermagem*, 18(2):149-155.

- Parkes, J., Caravale, B., Marcelli, M., Franco, F., & Colver, A. (2011). Parenting stress and children with cerebral palsy: a European cross-sectional survey. *Developmental Medicine & Child Neurology*, 53(9):815-821.
- Prudente, C.O.M., Barbosa, M.A. and Porto, C.C., (2010). Relation between quality of life of mothers of children with cerebral palsy and the children's motor functioning, after ten months of rehabilitation. *Revista Latino-Americana de Enfermagem*, 18(2):149-155.
- Robitail, S. Simeoni, M.C., Erhart, M. Ravens-Sieberer, U. Bruil, J. Auquier, P. and Group, E.K., (2006). Validation of the European proxy KIDSCREEN-52 pilot test health-related quality of life questionnaire: first results. *Journal of Adolescent Health*, 39(4):596-597.
- Rostami, H.R., Khayat-zadeh, M.M., Amir-salari, S. and Karimloo, M., (2013). Investigation of quality of life in mothers of children with cerebral palsy in Iran: association with socio-economic status, marital satisfaction and fatigue. *Disability and Rehabilitation*, 35(10):803-808.
- Sadeghi, M., Alipour, A., Abedi, A. and Ghasmi, N., (2013). The Effect of Life Skills Training on the Life Quality of Adolescent Orphans (Persian). *Social Welfare Quarterly*, 13(49):269-286.
- Sellier, E., Platt, M. J., Andersen, G. L., Krageloh-Mann, I., De La Cruz, J., & Cans, C. (2016). Decreasing prevalence in cerebral palsy: a multi-site European population-based study, 1980 to 2003. *Developmental Medicine & Child Neurology*, 58(1): 85-92.
- Sajedi, F., Alizad, V., Malek-khosravi, G., Karimlou, M. and Vameghi, R., (2010). Depression in mothers of children with cerebral palsy and its relation to severity and type of cerebral palsy. *Acta Medica Iranica Journal Impacta and Description*, 48(4):250.
- Sauve, L.J., Scheifele, D.W., Bettinger, J.A., Moore, D., Vaudry, W., Tran, D., Halperin, S.A. and Pelletier, L., (2010). Pandemic influenza in Canadian children: a summary of hospitalized pediatric cases. *Vaccine*, 28(18):3180-3184.

Soh, S.E., McGinley, J.L., Watts, J.J., Ianseck, R., Murphy, A.T., Menz, H.B., Huxham, F. and Morris, M.E., (2013). Determinants of health-related quality of life in people with Parkinson's disease: a path analysis. *Quality of life research*, 22(7):1543-1553.

Souza, N.D., Sardesai, V., Joshi, K., Joshi, V. and Hughes, M., (2006). The determinants of compliance with an early intervention programme for high- risk babies in India. *Blackwell Publishing Ltd Child: Care, Health & Development*, 32(1):63–72.

Susniene, D. and Jurkauskas, A., (2009). The concepts of quality of life and happiness correlation and differences. *Inzinerineekonomika-engineering economics*, 3(3):58-66.

Singogo, C., Mweshi, M. and Rhoda, A., (2015). Challenges experienced by mothers caring for children with cerebral palsy in Zambia. *South African Journal of Physiotherapy*, 71(1):6.

Sipal, R.F. and Sayin, U., (2013). Impact of perceived social support and depression on the parental attitudes of mothers of children who are deaf. *Journal of Child and Family Studies*, 22(8):1103-1111.

Sridhar, R. and Nirmala, D., (2015). Quality of Life among the Parents of Children with Cerebral Palsy. *Indian Journal of Applied Research*, 5:12

TeRzi, R. and Tan, G., (2016). Musculoskeletal system pain and related factors in mothers of children with cerebral palsy. *The journal of the Turkish Society of Algology*, 28(1):18.

Tekinarslan, I.L.K.N.U.R., (2013). A comparison study of depression and quality of life in Turkish mothers of children with Down syndrome, cerebral palsy, and autism spectrum disorder. *Psychological reports*, 112(1):11-13.

Tan, S.S., van Meeteren, J., Ketelaar, M., Schuengel, C., Reinders-Messelink, H.A., Raat, H., Dallmeijer, A.J., Roebroek, M.E. and PERRIN study group, (2014). Long-term trajectories of health-related quality of life in individuals with cerebral palsy: a



multicenter longitudinal study. *Archives of physical medicine and rehabilitation*, 95(11):2029-2039.

Tong, A., Henning, P., Wong, G., McTaggart, S., Mackie, F., Carroll, R.P. and Craig, J.C., (2013). Experiences and perspectives of adolescents and young adults with advanced CKD. *American Journal of Kidney Diseases*, 61:375–384.

Toorn, R.V., Laughton, B. and Zyl, N.V., (2007). Aetiology of cerebral palsy in children presenting at TygerbergHospital. *South African Journal of child Health*, 1:74-77.

Viehweger, E., Heinen, F., Desloovere, K., Schroeder, A.S., Berweck, S., Borggraefe, I., Campenhout, A., Andersen, G.L., Aydin, R., Becher, J.G., Bernert, G. and Caballero, I.M., (2010). The updated European Consensus 2009 on the use of Botulinum toxin for children with cerebral palsy. *European journal of paediatric neurology*, 14(1):45-66.

Varni, J.W., Burwinkle, T.M., Sherman, S.A., Hanna, K., Berrin, S.J., Malcarne, V.L. and Chambers, H.G., (2005). Health-related quality of life of children and adolescents with cerebral palsy: hearing the voices of the children. *Developmental Medicine & Child Neurology*, 47(09):592-597.

Von, Rueden, U., Gosch, A., Rajmil, L., Bisegger, C. and Ravens-Sieberer, U., (2006). Socioeconomic determinants of health related quality of life in childhood and adolescence: results from a European study. *Journal of epidemiology and community health*, 60(2):130- 135.

Van Doorslaer, E., O'Donnell, O., Rannan-Eliya, R. P., Somanathan, A., Adhikari, S. R., Garg, C. C., & Karan, A. (2006). Effect of payments for health care on poverty estimates in 11 countries in Asia: an analysis of household survey data. *The Lancet*, 368(9544):1357-1364.

Wolraich, M., Droter, D., Dworkin, P. and Perrin, E., (2008). Developmental-behavioral pediatrics. *Evidence Based Practice*, 14:483-517.

White-Koning, M., Arnaud, C., Dickinson, H.O., Thyen, U., Beckung, E., Fauconnier, J., McManus, V., Michelsen, S.I., Parkes, J. and Schirripa, G., (2007). Determinants of

child- 55 parent agreement in quality-of-life reports: a European study of children with cerebral palsy. *Pediatrics*, 120(4):804-814.

Zani, A. V., Merino, M. D. and Marcon, S. S., (2013). The feelings and experience of a mother facing Down syndrome. *ActaScientiarum. Health Sciences*, 35(1):67-75.

## **APPENDIX**

IRB Permission Letter

Permission Letter

Inform consent (English)

Inform consent (Bangla)

Questionnaire (English)

Questionnaire (Bangla)



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

(The Academic Institute of CRP)

Ref.

CRP-BHPI/TRB/11/18/1273

Date: 14/11/2018

To  
Uarda All Rifa Trina  
B.Sc. in Physiotherapy  
Session: 2013-2014, Student ID:112130222  
BHPI, CRP, Savar, Dhaka-1343, Bangladesh

**Subject: Approval of the thesis proposal "Quality of life among mother of school going children with cerebral palsy" by ethics committee.**

Dear Uarda All Rifa Trina,  
Congratulations,

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

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

The purpose of the study is to determine quality of life among mother of school going children with cerebral palsy. The study involves use of a WHOQOL-BREF questionnaire to identify quality of life of mother with cerebral palsy school going children that may take 20 to 30 minutes to answer questionnaire. There is no likelihood of any harm to the participants and participation in the study may benefit the participants or other stakeholders. The members of the Ethics committee have approved the study to be conducted in the presented form at the meeting held at 9.30 AM on 24<sup>th</sup> January, 2018 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, সাজার, 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

Date: 22-07-2018

To,

The Principal,

William and Marie Taylor School

CRP-Chapain, Savar, Dhaka-1343

**Subject: Prayer for seeking permission to collect data for conducting a research project.**

Sir,

With due respect and humble submission I am Uarda All Rifa Trina, student of 4<sup>th</sup> year B.Sc. in physiotherapy at Bangladesh Health Professions Institute (BHPI). In 4<sup>th</sup> year we have to do a research project for the partial fulfillment of the requirement for the degree of B.Sc. in physiotherapy. My research project title is "Quality of life among mother of school going children with cerebral palsy" under the supervision of Md. Obaidul Haque, professor & Head of the Physiotherapy Department, BHPI. I want to collect research data for my research project from the mother of students of William and Marie Taylor School, CRP- Savar. So, I need permission for data collection from the William and Marie Taylor School, CRP-Savar. I would like to assure that anything of my research project will not be harmful for the participants and the department as well.

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

Yours faithfully,

Uarda All Rifa Trina

Uarda All Rifa Trina

Roll: 27

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

Session: 2013-2014

Bangladesh Health Professions Institute

(An academic Institution of CRP)

CRP- Chapain, Savar, Dhaka-1343.

*Recommended & Forwarded*  
*22.07.18*

*Prof. Md. Obaidul Haque*  
Head, Department of Physiotherapy  
Bangladesh Health Professions Institute (BHPI)  
CRP, Savar, Dhaka-1343

*N. Islam*  
*22.07.18*  
Md. Nurul Islam (Citron)  
In-Charge  
Special Education Needs Unit  
CRP

Date: 18-7-2018

To,

Head of the Department of Physiotherapy,  
Bangladesh Health Professions Institute,  
CRP-Chapain ,Savar,Dhaka-1343

**Subject: Prayer for seeking permission to collect data for conducting a research project.**

Sir,

With due respect and humble submission I am Uarda All Rifa Trina, student of 4<sup>th</sup> year B.Sc. in physiotherapy at Bangladesh Health Professions Institute(BHPI).In 4<sup>th</sup> year we have to do a research project for the partial fulfillment of the requirement for the degree of B.Sc. in physiotherapy. My research project title is **"Quality of life among mother of school going children with cerebral palsy"**under the supervision of Md. Obaidul Haque, professor & Head of the Physiotherapy Department, BHPI .Conducting this research project is partial fulfillment of the requirement for the degree of B.Sc. in physiotherapy. I want to collect research data for my research project from mother of students of William and Marie Taylor School, CRP- Savar. So, I need permission for data collection from the William and Marie Taylor School, CRP-Savar. I would like to assure that anything of my research project will not be harmful for the participants and the department as well.

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

Yours faithfully,

Uarda All Rifa Trina

Uarda All Rifa Trina

Roll: 27

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

Session: 2013-2014

Bangladesh Health Professions Institute

(An academic Institution of CRP)

CRP- Chapain, Savar, Dhaka-1343.

*Sr. Slab BHPi*  
*Issue a letter*  
*22/07/18*  
Prof. Md. Obaidul Haque  
Head, Department of Physiotherapy  
Bangladesh Health Professions Institute (BHPI)  
CRP, Savar, Dhaka-1343

## CONSENT STATEMENT

Assalamualaikum,

I am Uarda all rifa Trina student of physiotherapy department affiliated to university of Dhaka. I am conducting this study for 4<sup>th</sup> professional B.sc in Physiotherapy project study dissertation titled **“Quality of life among mother of school going 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 approximately 20-30 minutes.

I would like to inform you that this is a purely academic study and will not be used for any other purpose. Your participation in the research will have no impact on your present workplace. All information provided by you will be treated as confidential and in the event of any report or publication it will be ensured that the source of information remains anonymous.

Your participation in this study is voluntary and honorarium will not be provided for this purpose. you may withdraw yourself at any time during this study without any negative consequences. You also have the right not to answer a particular question that you don't like or do not want to answer during interview.

If you have any query about the study or your right as a participant, you may contact with me at Physiotherapy Department, BHPI, CRP, Savar, Dhaka-1343.

Do you have any questions before I start?

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

Yes

No

Signature of the Participant and date \_\_\_\_\_

Signature of the Data collector and date \_\_\_\_\_

Signature of the researcher and date \_\_\_\_\_

## সম্মতিপত্র

আসসালামুয়ালাইকুম,

আমি ওয়ার্দাআলরিফাতুণা, আমি বাংলাদেশ হেলথ প্রফেশনস ইনস্টিটিউট (বিএইচপিআই)-  
এরফিজিওথেরাপিবিভাগের ৪র্থ বর্ষেরএকজন  
ছাত্রী। এইপ্রতিষ্ঠানটিঢাকাবিশ্ববিদ্যালয়েরঅধিভুক্ত। আমারকোর্সেরঅংশহিসেবেআমিএকটিগবেষণাকরছি।

আমার গবেষণার শিরোনাম “বিদ্যালয়গামীসেরিব্রাল পালসি  
শিশুদেরমায়েদেরজীবনযাত্রারমান”। গবেষণার মাধ্যমে আমি বিদ্যালয়গামী সেরিব্রাল পালসি শিশুদের  
সঙ্গে তাদের মায়েদের জীবনযাত্রার মান এবং শিশুদের বয়সের সাথে বিভিন্ন কর্মকান্ডের সম্পর্ক দেখবো।  
আমি এখন আপনাকে কিছু ব্যক্তিগত এবং কর্ম সম্পর্কে কিছু প্রশ্ন করতে চাচ্ছি। এতে আনুমানিক ২০-৩০  
মিনিট সময় নিবে।

আমি আপনাকে অবগত করছি যে, এটা আমার গবেষণার অংশ এবং যা অন্য কোন উদ্দেশ্যে ব্যবহৃত হবে  
না। এই গবেষণায় আপনার অংশগ্রহণ বর্তমান কর্মস্থলে কোন প্রকার প্রভাব ফেলবে না। আপনি যেসব  
তথ্য প্রদান করবেন তার গোপনীয়তা বজায় থাকবে এবং আপনার প্রতিবেদনের ঘটনা প্রবাহে এটা  
নিশ্চিত করা হবে যে এই তথ্যের উৎস অপ্রকাশিত থাকবে।

এই গবেষণায় আপনার অংশগ্রহণ স্বেচ্ছাপ্রণোদিত এবং আপনি এর জন্য কোনো পারিশ্রমিক পাবেন না,  
আপনি যেকোন সময় এই গবেষণা থেকে কোন নেতিবাচক ফলাফল ছাড়াই নিজেকে প্রত্যাহার করতে  
পারবেন। এছাড়াও কোন নির্দিষ্ট প্রশ্ন অপছন্দ হলে উত্তর না দেয়ার এবং সাক্ষাৎকারের সময় কোন উত্তর  
না দিতে চাওয়ার অধিকারও আপনার আছে।

এই গবেষণায় অংশগ্রহণকারী হিসেবে যদি আপনার কোন প্রশ্ন থাকে তাহলে আপনি আমাকে অথবা  
আমার সুপারভাইজার মোহাম্মদ ওবায়দুল হক, অধ্যাপক ও বিভাগীয় প্রধানফিজিওথেরাপী বিভাগ,  
বিএইচপিআই, সিআরপি, সাভার, ঢাকা-১৩৪৩ তে যোগাযোগ করতে পারেন।

সাক্ষাৎকার শুরু করার আগে কি আপনার কোন প্রশ্ন আছে ?

সুতরাং আমি আপনার অনুমতিতে এই সাক্ষাৎকার শুরু করতে পারি ?

হ্যাঁ না

১। অংশগ্রহণকারীর স্বাক্ষর ও তারিখ \_\_\_\_\_

২। সাক্ষীর স্বাক্ষর ও তারিখ \_\_\_\_\_

৩। গবেষকের স্বাক্ষর ও তারিখ \_\_\_\_\_



**“Quality of life among the mother of school going children with cerebral palsy.”**

<b>Patient’s identification</b>			
Name:			
Address: District:	Thana:	Post office:	Village:
Mobile No:			

**Part 1: Patient's socio-economic background information**

Serial no.	Question	Coding Category	Scripto
1.1	School Name:		
1.2	Age(Children):		
1.3	Age(Mother):		
1.4	Gender (Children)	1.Boy 2.Girl	
1.5	Gender		
1.6	Mother's educational qualification	1.Uneducated 2.Primary 3.Secondary 4.Higher Secondary 5.Graduate 6.Post graduate 7.Others.....	
1.7	Mother’s occupation	1.House wife 2.Employer 3.Teacher	

		4.Day labor 5.Others.....	
1.8	Monthly Income of mother	1.3000-5000 2.5000-10000 3. More than 10000 4. Others.....	
1.9	Marital status	1.Married 2. Widow 3. Divorce separation 4.Others.....	
1.10	What happened in the marriage relationship?	1.Yes 2.No	If yes answer to the question 1.11
1.11	What was the relation between you?		
1.12	What was the injury during the baby's birth?	1.Yes 2.No	If yes answer to the question 1.13
1.13	What was the injury	1.Injury to the head 2.Injury to the brain 3.Others.....	
1.14	Is there a history of addiction to the mother?	1.Yes 2.No	If yes answer to the question 1.15
1.15	What was the type of addiction?	1.Cigarette	

		2.Tobacco 3.Jarda 4.Others.....	
1.16	Types of cerebral palsy: According to muscle tension and involvement of muscle what is the injury?	1. Involuntary muscle contraction. 2. Flaccid type of muscle contraction. 3. Muscular imbalance. 4. Mixed	

### WHOQOL-BREF

Please read each question, assess your feelings, and circle the number on the scale for each question that gives the best answer for you. Please read each question, assess your feelings, and circle the number on the scale for each question that gives the best answer for you.

2.1	How would you rate your quality of life?	Very poor 1	Poor 2	Neither poor nor good 3	Good 4	Very good 5
-----	--	----------------	-----------	----------------------------	-----------	----------------

2.2	How satisfied are you with your health?	Very dissatisfied 1	Dissatisfied 2	Neither satisfied nor dissatisfied 3	Satisfied 4	Very Satisfied 5
-----	---	------------------------	-------------------	---	----------------	---------------------

The following questions ask about how much you have experienced certain things in the last four weeks.

2.3	1	2	3	4	5
2.4	1	2	3	4	5

2.5	1	2	3	4	5
2.6	1	2	3	4	5

		Not at all	A little	A moderate Amount	Very much	Extremely
2.7	How well are you able to concentrate?	1	2	3	4	5
2.8	How safe do you feel in your daily life?	1	2	3	4	5
2.9	How healthy is your physical environment?	1	2	3	4	5

The following questions ask about how completely you experience or were able to do certain things in the last four weeks.

		Not at all	A little	Moderately	Mostly	Completely
2.10	Do you have enough energy for everyday life?	1	2	3	4	5
2.11	Are you able to accept your bodily appearance?	1	2	3	4	5
2.12	Have you enough money to meet your needs?	1	2	3	4	5
2.13	How available to you is the information that you need in your day-to-	1	2	3	4	5

	day life?					
2.14	To what extent do you have the opportunity for leisure activities?	1	2	3	4	5
2.15	How well are you able to get around?	Very poor 1	Poor 2	Neither poor nor good 3	Good 4	Very good 5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
2.16	How satisfied are you with your sleep?	1	2	3	4	5
2.17	How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
2.18	How satisfied are you with your capacity for work?	1	2	3	4	5
2.19	How satisfied are you with yourself?	1	2	3	4	5
2.20	How satisfied are you with your personal relationships	1	2	3	4	5
2.21	How satisfied are you with your sex life?	1	2	3	4	5
2.22	How satisfied are you with the support you get from your friends?	1	2	3	4	5
2.23	How satisfied are you with the conditions of your living place?	1	2	3	4	5

2.24	How satisfied are you with your access to health services?	1	2	3	4	5
2.25	How satisfied are you with your transport?	1	2	3	4	5

The following questions ask you to say how good or satisfied you have felt about various aspects of your life over the last four weeks

The following question refers to how often you have felt or experienced certain things in the four weeks

2.26	How often do you have negative feelings such as blue mood, despair, anxiety, depression?	Never 1	Seldom 2	Quite often 3	Very often 4	Always 5
------	--	------------	-------------	------------------	-----------------	-------------

“বিদ্যালয়গামীসেরেব্রাল পালসি শিশুদেরমাতাদেরজীবনযাত্রারমান”

নামঃ			
সাক্ষাতকারের তারিখঃ			
ঠিকানাঃ জেলাঃ	থানাঃ	ডাকঘরঃ	গ্রামঃ
মোবাইল নাম্বারঃ			

পর্ব ১ঃ রোগীর আর্থ সামাজিক প্রেক্ষাপট তথ্য

ক্রমিক নং	প্রশ্নাবলী	কোডিং ক্যাটাগরি	স্কীপটু
১.১	বিদ্যালয়ের নামঃ		
১.২	বয়স(সন্তানের)ঃ		
১.৩	বয়স(মাতার)ঃ		
১.৪	লিঙ্গঃ	১.পুরুষ ২. মহিলা	
১.৫	লিঙ্গ (সন্তানের)ঃ	১.ছেলে ২. মেয়ে	
১.৬	মাতারশিক্ষাগতযোগ্যতাকি?	১.অশিক্ষিত ২.প্রাথমিক ৩.মাধ্যমিক ৪.উচ্চমাধ্যমিক ৫.স্নাতক ৬.স্নাতকোত্তর ৭.অন্যান্য.....	
১.৭	মাতার পেশা কি?	১.গৃহিণী ২.চাকুরীজীবী ৩.শিক্ষক	

		৪.দিনমজুর ৫.অন্যান্য.....	
১.৮	আপনাদের মাসিক আয় কত?	১.৩০০০-৫০০০ ২.৫০০০-১০০০০ ৩.১০০০০ এর বেশি ৪.অন্যান্য.....	
১.৯	বৈবাহিক অবস্থা?	১.বিবাহিত। ২.বিধবা ৩.বিবাহ বিচ্ছেদ ৪।অন্যান্য.....	
১.১০	আত্মীয় সম্পর্কে বিবাহ	১.হ্যাঁ ২.না	যদি হ্যাঁ হয় তাহলে ১.১১ নং প্রশ্নের উত্তর দিন।
১.১১	আপনাদের মধ্যে আত্মীয়তার সম্পর্ক কী ছিল?		
১.১২	বাচ্চা জন্মের সময় কোন আঘাত পেয়েছিল কি?	১.হ্যাঁ ২.না	যদি হ্যাঁ হয় তাহলে ১.১৩ নং প্রশ্নের উত্তর দিন।
১.১৩	কী ধরনের আঘাত ছিল?	১.মাথায় আঘাত ২.শ্লায়তে আঘাত ৩।অন্যান্য.....	
১.১৪	মাতার নেসা করার ইতিহাস আছে কী ?	১.হ্যাঁ ২.না	যদি হ্যাঁ হয় তাহলে ১.১৫ নং প্রশ্নের উত্তর দিন।
১.১৫	কি ধরনের আসক্তি ছিল?	১.সিগারেট ২.তামাক ৩.জর্দা ৪.অন্যান্য.....	
১.১৬	সেরেব্রাল পালসির প্রকারভেদঃ মাৎস্পেশীর টান এবং বিস্তৃতি অনুসারে কেমন?	১.মাৎস্পেশীর অনৈচ্ছিক আক্ষেপজনিত সমস্যা। ২.মাৎস্পেশীর নরম আক্ষেপজনিত সমস্যা।	



		৩.ভারসাম্য জনিত সমস্যা ৪.মিশ্রন	
--	--	------------------------------------	--

### WHOQOL-BREF

আপনার জীবনের গতচার সপ্তাহের কথা স্মরণ করুন এবং সবগুলো প্রশ্ন পড়ুন, আপনার অনুভূতি যাচাই করুন এবং পাশের ছকে যে উত্তরটি সবচেয়ে সঠিক মনে হবে সে নম্বরটিতে বৃত্ত তৈরি করুন।

		খুব খারাপ	খারাপ	ভাল ও না মন্দ ও না	ভাল	খুব ভাল
২.১	আপনার জীবন যাত্রার মান কেমন?	১	২	৩	৪	৫
		খুব অসন্তুষ্ট	অসন্তুষ্ট	সন্তুষ্ট নয় অসন্তুষ্ট নয়	সন্তুষ্ট	খুব সন্তুষ্ট
২.২	আপনার স্বাস্থ্য নিয়ে আপনি কি সন্তুষ্ট	১	২	৩	৪	৫

নিচের প্রশ্ন গুলো গত চার সপ্তাহের নিম্নবর্ণিত অভিজ্ঞতা গুলো কি পরিমাণে হয়েছে সে সম্পর্কে

		একদমনা	কম	মোটামুটি	বেশি	খুববেশি
২.৩	শারীরিক ব্যথার জন্য আপনি কি পরিমাণ প্রয়োজনীয় কাজ থেকে বিরত ছিলেন?	১	২	৩	৪	৫
২.৪	আপনার দৈনন্দিন কার্যক্রম ঠিক রাখতে চিকিৎসা কতটুকু প্রয়োজন।	১	২	৩	৪	৫
২.৫	আপনি জীবনকে কতটুকু উপভোগ করেন।	১	২	৩	৪	৫
২.৬	জীবনকে আপনার কতটুকু অর্থ পূর্ণ মনে হয়।	১	২	৩	৪	৫
২.৭	আপনি কাজে কতটুকু মনসংযোগ করতে পারেন।	১	২	৩	৪	৫
২.৮	আপনি দৈনন্দিন জীবনে কতটুকু নিরাপত্তা অনুভব করেন।	১	২	৩	৪	৫
২.৯	আপনার ভৌত পরিবেশ কতটুকু স্বাস্থ্যকর	১	২	৩	৪	৫

নিচের প্রশ্নগুলিতে জানতে চাওয়া হইয়েছে গত চার সপ্তাহে আপনি কতটুকু সম্পূর্ণ ভাবে কোন কাজ করতে বা অভিজ্ঞতা লাভ করতে পেরেছেন।

২.১০	আপনার কি প্রতিদিন কাজ করার মত শক্তি আছে।	১	২	৩	৪	৫
২.১১	আপনি কি আপনার শরীরের গড়ন নিয়ে সন্তুষ্ট?	১	২	৩	৪	৫
২.১২	আপনার কি প্রয়োজন মেটাতে যথেষ্ট টাকা আছে?	১	২	৩	৪	৫
২.১৩	আপনি কি দৈনন্দিন জীবন যাপনের জন্য প্রয়োজনীয় তথ্য পান।	১	২	৩	৪	৫
২.১৪	অবসর কাটানো/ বিনোদনের সুযোগ আপনার কতটুকু আছে?	১	২	৩	৪	৫
২.১৫	আপনি কতটা ভালভাবে চলা ফেরা করতে পারেন?	১	২	৩	৪	৫

নিচের প্রশ্নে জানতে চাওয়া হয়েছে গত চার সপ্তাহের আপনার জীবনের বিভিন্ন দিক নিয়ে আপনি কতটুকু সন্তুষ্ট।

২.১৬	আপনার ঘুম নিয়ে আপনি কতটা সন্তুষ্ট?	১	২	৩	৪	৫
২.১৭	দৈনন্দিন কাজ করার ক্ষমতা নিয়ে আপনি কতটুকু সন্তুষ্ট?	১	২	৩	৪	৫
২.১৮	আপনার কাজ করার ক্ষমতা/দক্ষতা নিয়ে আপনি কতটুকু সন্তুষ্ট?	১	২	৩	৪	৫
২.১৯	নিজেকে নিয়ে আপনি কতটুকু সন্তুষ্ট?	১	২	৩	৪	৫
২.২০	অন্যদের সাথে আপনার ব্যক্তিগত সম্পর্ক সমূহ নিয়ে আপনি কতটুকু সন্তুষ্ট?	১	২	৩	৪	৫
২.২১	আপনার যৌন জীবন নিয়ে আপনি কতটুকু সন্তুষ্ট?	১	২	৩	৪	৫
২.২২	বন্ধুদের কাছ থেকে সাহায্যে আপনি কতটুকু সন্তুষ্ট?	১	২	৩	৪	৫
২.২৩	আপনি আপনার বাসস্থানের অবস্থা নিয়ে কতটুকু সন্তুষ্ট?	১	২	৩	৪	৫

২.২৪	আপনি যে স্বাস্থ্য সেবা পান তাতে কি সন্তুষ্ট ?	১	২	৩	৪	৫
২.২৫	আপনি যাতায়াত ব্যবস্থা নিয়ে কতটুকু সন্তুষ্ট ?	১	২	৩	৪	৫

নিচের প্রশ্নে জানতে চাওয়া হয়েছে গত চার সপ্তাহের ঐ নির্দিষ্ট বিষয় সমূহ আপনি কতবেশি / ঘনঘন অনুভব করেছেন?

২.২৬	আপনার হতাশা, উদ্বেগ, অবসন্নতা এইসব নেতিবাচক অনুভূতি কত ঘন ঘন হয় ।	১	২	৩	৪	৫
------	--	---	---	---	---	---