HEALTH RELATED QUALITY OF LIFE OF CHILDERN WITH CEREBRAL PALSY AMONG 3-12 YEARS OLD

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

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Declaration

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

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Acronyms

BHPI : Bangladesh Health Professions Institute

CP : Cerebral Palsy

CRP : Centre for the Rehabilitation of the Paralysed

HRQL : Health Related Quality of Life

IRB : Institutional Review Board
LAS : Life Assessment Scale

LAQ : Life Assessment Questionnaire

QL : Quality of Life

SPSS : Statistical Package for the Social Science

WHO : World Health Organization

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Abstract

Purpose: Identify the quality of life of mother of children with cerebral palsy. *Objectives:* To determine the health related quality of life of children with cerebral palsy. To find out the level of physical independence, mobility, clinical burden, social burden, social integration and manage schooling. ***Methodology:*** This study was conducted using cross sectional prospective survey under a quantitative study design with 100 participants of cerebral palsy children among 3-12 years old. A structured Life Assessment Questionnaire (LAQ) and demographic information chart was using as a data collection instrument. LAQ-CP questionnaire evaluates the impact of disability in children with CP and their families. It has 46items, organized into six dimensions: physical independence, mobility, clinical burden, schooling, economic burden, and social integration. Based on scores in each item, dimensional scores and a final standard score, known as Lifestyle Assessment Score (LAS) is obtained. These are expressed as a percentage score. The classification of the HRQOL according to LAS is as follows: Good (<30%); mildly-affected (30-50%); moderately-affected (51-70%); and severely-affected (>70%). ***Results:*** Data was analyzed with the software named Statistical Package for the Social Science (SPSS) version 20. Microsoft office Excel 2010 was used to decorating the bar graph and pie charts. The result of this study was consisted of quantitative data. By this study a lot of information was collected. The mean age of the respondents was 7.8 years with a standard deviation of 2.93. Majority of the respondents (52%) were 8 to 12 years old followed by 3 to 7 years old (48%). According to analysis the mean score of mobility is 2.37.That means highest number of 2.37 children affected in mobility. For those activities maximum children have need maximum to minimum assistance. The mean score of schooling is 2.15. That means 2.15 children affected in schooling. Analysis shows that the mean score of physical independence is 1.84. That means 1.84 children moderately affected in physical independence. The mean score of social integration 1.78 means 1.78 children are affected in social integration. Mean score of economic burden 1.46 means 1.46 children are affected in economic burden. The mean score 1.34 of clinical burden means 1.34 children affected in clinical burden.

Keywords: Cerebral Palsy, Quality of life, LAQ.

CHAPTER-I INTRODUCTION

1.1 Background

Cerebral palsy (CP) describes a group of disorders of movement and posture that are attributed to non-progressive disturbances in the developing brain. Movement and posture problems in CP include walking and balance, gross and fine motor control, and muscle spasticity. These problems may lead to impairments in physical fitness and physical activity levels in persons with CP. Reduced physical fitness and physical activity can interact to cause a cycle of de-conditioning: low physical fitness might result in high physical strain during activities of daily living (ADL), possibly leading to a reduction in activity and consequently, further decreasing physical fitness. Moreover, physical fitness is known to contribute to health and quality of life of persons with chronic conditions (Nooijen et al, 2014).

Cerebral Palsy (CP) defines a group of conditions, arising from an injury to the developing brain and occurs in 2.0 children per 1000 live births. In addition to the disturbances of movement and posture including spasticity, muscle weakness and reduced coordination, common impairments of children with CP include disturbances of sensation, perception, cognition, communication, behavior, epilepsy, and secondary musculoskeletal problems. Reduced activity levels and participation restrictions due to these impairments may lead to a reduced quality of life (QOL), compared to their typically developing peers (Carlon et al, 2010).

Cerebral palsy is the most common condition that is responsible for the child disability. The calculation based on estimations and forecasts of the U.S. Bureau of the census, International data base indicate that in 2010 the number of patients with the infantile cerebral palsy (ICP) were increase to 17340000 people in the world (cerebral palsy statistics, 2010). According to statistics population with cerebral palsy in USA exceeded 75000. Currently there are more than 10000 new cases occur each year. In developed countries, International assessments propose that CP affects between 1.2 and 3.0 per 1000 children (Hustad et al., 2011). The incidence of CP is considered to be 2 to 2.5 in 1000 live births and the prevalence of CP in the developing countries tends to be in a similar range (Bialik & Givon, 2009). In one study found that prevalence of cerebral palsy in Bangladesh was 6.1/1000 children (Tabib, 2009). Bangladesh has recently seen an increase in the number of children diagnosed with cerebral palsy. According to disability profile, the client assess in the Shishu Bikash Clinic (Rural Centre) during January to December 2009 showed a report of child disability were 42% of total disability was cerebral palsy, among these spastic cerebral palsy is 9%, Athetoid cerebral palsy is 2%, Ataxic cerebral palsy is 3% and rest of the patient is other type of cerebral palsy (Khan & Rahman, 2009).

Gage's study stated that cerebral palsy is primarily characterized by central nervous system abnormalities, such as loss of selective motor control and abnormal muscle tone. As a result of growth these primary characteristics often lead to secondary deficits, including bony deformities, muscle contractures and gait abnormalities and among all type of cerebral palsy spastic cerebral palsy is the most common type of cerebral palsy (Behrman, 2004).

Sunder (2010) had described that cerebral palsy is not a single or any illness. The disability of CP persistent and caused by a non progressive brain lesion arising before, during or after birth, during the period of brain development. CP is a disorder of movement and posture that is caused by a non progressive brain lesion that occurs in uterus during or shortly after birth and is expressed throw variable impairments in the co-ordination of muscles action and sensation.

Damage of one or more parts of the brain affect the ability to control muscles in CP. Symptoms range from mild to severe but the condition does not get worse with the Child's age (Cerebral Palsy statistics, 2010).

QoL is a broad evaluation of human function in a variety of domains. The internationally accepted definition of QoL, as defined by the World Health Organization Quality of Life (WHOQOL) Group, is the individual's perception of his or her position in life in the context of the culture and value systems in which he or she lives in relation to goals, expectations, standards and concerns (WHO).

HRQoL is a part of QoL. It is the patients' own evaluation of functioning in the physical, psychological and social domains. Compared with QoL, HRQoL is measured using fewer domains. Hence, evaluation of HRQoL is not as extensive as the assessment of QoL (Hamming and Veries, 2007).

1.2 Rationale

The incidence of cerebral palsy worldwide is between 2 to 2.5 cases per 1,000 births (Marron et al., 2013) and gives burden on parents both physically and psychologically. Cerebral palsy is a chronic condition that has serious consequences for physical, cognitive and behavior functioning. In recent years there has been increasing interest in measuring the quality of life of children with cerebral palsy.

Cerebral palsy is neurodevelopment condition, is the common “physical” disability in childhood and severely affects a child's development. It is a neurological disorder and the prevalence of this disorder is increasing day by day. Due to their challenging behavior and interest those child need always high supervision and care-giving. It is important to conduct the study because it will provide a better awareness about the impact on the mother or carer’s life of having a cerebral palsy child. This awareness is very necessary to understand their problems and their needs. It will also help therapists to provide effective family education to mother and carer by increasing their knowledge about cerebral palsy and changing their attitudes towards CP. Quality of life is not only concept of illness, functional status, mental health and comfort but also parental impact and family functioning. The aim of the study is to find out the quality of life of children with cerebral palsy, factors that influence it and how it compares with quality of life of the general population. This study will be helpful for physiotherapist to make awareness about children with cerebral palsy. Physiotherapy plays a vital role to develop the quality of life of cerebral palsy child. It will also help other health professionals such as social workers, counselors, and Psychiatrists on this topic. So it will be also helpful for physiotherapist to work in this area for delivering treatment.

1.3 Operational definition

Cerebral palsy

Cerebral Palsy is defined as a group of non-progressive, but often changing, motor impairment syndromes secondary to lesions or anomalies of the brain arising in the early stages of its development.

Quality of life

The general wellbeing of individuals and societies.

Health

According to WHO "A state of complete physical, mental and social well-being and not merely the absence of disease".

Physical health

Physical health means a good body health which is a healthy because of regular physical activity, good nutrition and adequate rest.

Mental function

Mental function is terms often used interchangeably for the entire thing that individuals can do with their minds.

Social function

Any public gathering, like a party or school graduation.

1.4 Research question

What is the health related quality of life of children with cerebral palsy?

1.5 Objectives

1.5.1 General objective

To determine the health related quality of life of children with cerebral palsy.

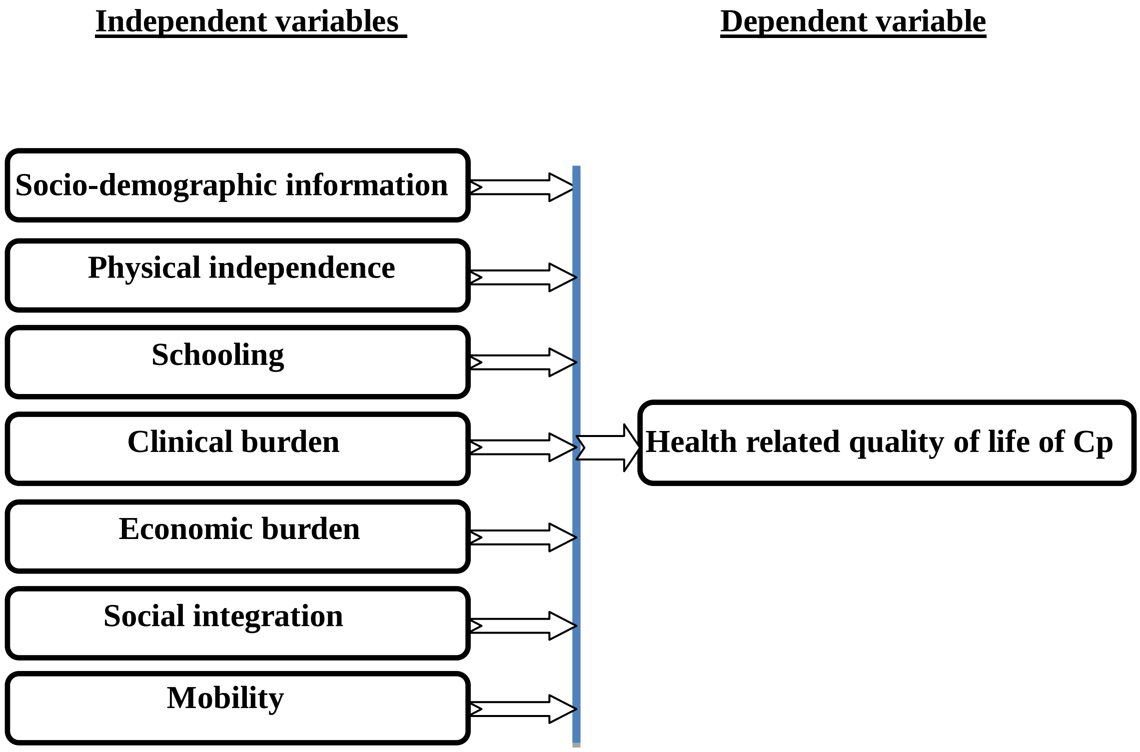
1.5.2 Specific objectives

-To find out the socio-demographic (age, gender, residential area) information.

-To find out the level of physical independence.
-To find out the level of mobility.
-To find out the level of clinical burden.
-To find out the level of economic burden.
-To find out the ability to manage schooling.
-To explore the social integration.

1.6 List of variable

Conceptual Framework



CHAPTER-II LITERATURE REVIEW

‘Cerebral’ refers to the brain and ‘Palsy’ to a disorder of movement or pressure. If someone has cerebral palsy it means because of an injury to the brain (cerebral) he or she is not able to use some of the muscles of body in normal way (palsy) .CP is a group of condition that affects the movement and posture of body.

Cerebral palsy is the most common neuro developmental motor disability in children. The condition requires medical, educational, social, and rehabilitative resources throughout the lifespan (Hussain et al., 2012). Amin et al. (2015) stated cerebral palsy (CP) describes a group of permanent disorders of the development of movement and posture, causing activity limitations that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. There is no definite cause of cerebral palsy rather some risk factors contribute to the development of CP during prenatal, natal or postnatal period (Tatla et al., 2013). 70 to 80% of cerebral palsy cases are acquired prenatally with unknown causes and birth complications, including asphyxia, are currently estimated to account for about 6 % of patients with congenital cerebral palsy, on the other hand neonatal risk factors for cerebral palsy include first cousin marriage 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), Pre-eclampsia affects 3-5% of pregnant women and is characterized by maternal hypertension and proteinuria occurring after 20 weeks of gestation (Melheim et al., 2013). The pathological changes start when the specific causes resulting in neural damage and ending up with impaired neural connectivity as well as transmission. 10-15% of cerebral palsy cases are found during birth including prolongs labour, sudden birth, birth asphyxia, baby did not cry immediate after birth or by forceps delivery (Bangash et al., 2014). Postnatal causes include toxic, infectious meningitis, encephalitis, traumatic such as drowning. There is also a relation between coagulopathies causing cerebral infarction and particularly hemiplegic type of CP. Postnatal events account for 12% – 21% of CP. But in a large number of cases, the causes of CP remain unknown (Kułak et al., 2014).

Cerebral palsy is a neurological disorder the signs or symptoms of cerebral palsy may appear soon after birth or may take several months (Mandal, 2013). The most common early sign of cerebral palsy is developmental delay. Delay in reaching key growth milestones such as rolling over, sitting, crawling and walking are cause for concern. Physicians will also look for signs such as abnormal muscle tone, unusual posture, persistent infant reflexes and early development of hand preference (My child, 2013). Common signs of severe CP that may be noticed shortly after birth include: problems sucking and swallowing, weak or shrill cry, seizures and unusual positions. Often the body is either very relaxed or floppy or very stiff. In some severe cases many signs and symptoms are not readily visible at birth except and may appear within the first three to five years of life as the brain and child developed (My child, 2013). Severe motor and coordination impairment also occur (Mandal, 2013). Drooling is another but common symptom among children with CP. Children has movement and postural disorder associated with many disabilities such as- including intellectual disability, hearing and visual deficits, nutrition, feeding and swallowing problems, respiratory infections and epilepsy. Cerebral palsy suffers for long term and it affect activities of daily living and quality of life (Bell et al., 2010). The symptoms of cerebral palsy include: excessive drooling, difficulty swallowing, sucking or speaking, tremors, and trouble with fine motor skills such as fastening buttons or holding a pencil, stiff or tight muscles, low muscle tone, exaggerated reflexes, uncontrolled body movement, toe walking, limping or dragging a foot while walking, walking with a scissor gait, turning in their legs as they walk. Children with cerebral palsy can also have feeding problems, mental retardation, seizures, learning disabilities and problems with their vision and hearing. The symptoms don't worsen with age but symptoms can range from mild to severe (Iannelli, 2008). Signs can appear during several stages of early life. They include: neonatal early Infancy (0-3 Months): high pitched cry, poor neck control, excessive lethargy or irritability, weak suck or tongue thrust or tonic bite, oral hypersensitivity, decreased interest in surroundings, stiff or floppy posture, abnormal or prolonged reflexes. Later infancy-inability to perform motor skills control of hand grasp by 3 months, rolling over by 5 months and independent sitting by 7 months. Abnormal developmental patterns: hand preference by 12 months, excessive arching of back, prolonged or abnormal parachute response, and logrolling. Abnormal developmental patterns after 1 year of age: W sitting means both knee flexion, legs extremely rotation, bottom shuffling means scoots along the floor, tiptoe walking or hopping (Gershon et al., 2013).

CP is classified into four categories according to the type of disturbance in movement: Spastic cerebral palsy is the most common type of CP. This affects approximately 70 to 80 percent of individuals with the disorder. It occurs due to damage of motor cortex of the brain (cerebral palsy statistics, 2010). In this type of CP muscle become stiff and the child face difficulty to move the body parts (cerebral palsy statistics, 2010). There are varying degrees of spastic cerebral palsy. Some patients have mild causes that affect vary few movement and some have moderate spasticity. Other with more severe causes can have their entire bodies affected. Spastic cerebral palsy also limits stretching of muscle in daily activity and causes the development of muscle and joints deformity. Children born with spastic cerebral palsy do not have any deformity of the extremity but develop them over time due to joint contracture (Brody, 2009).

According to Raj (2009), this is a rare form of cerebral palsy which affects an estimated 5 to 1o percent of individuals with cerebral palsy. Ataxic cerebral palsy affects sense of balance and depth perception. Ataxic cerebral palsy is caused by damage to the cerebellum that is responsible for balance and coordination and coordinates the actions for different groups of muscle. Ataxic cerebral palsy therefore affects coordination of movement. Ataxic cerebral palsy usually affects all four limbs and trunk. Typically, persons affected by ataxic cerebral palsy have poor coordination, unsteady walking and difficulty with precise movements such as using a pen or buttoning a shirt.

The athetoid children have certain features in common. Tone is abnormal and varies in character & intensity, ranging in the one child from hypotonia to hypertonia, frequently with surprisingly sudden fluctuations. Involuntary movement occurs which may not be movements at all but really tonus changes, and the lower the tone the greater the fluctuation appears to be. These tonus changes may occur as intermittent tonic spasms occurring in recognizable patterns, or as repetitive rhythmical movements, or as fleeting, irregular and localized contraction of muscle groups, muscle or muscle fibres. These children show little or no co-contraction, therefore are unable to maintain aposture or develop enough fixation for a moving limb. There is poor grading between the agonist and antagonists during a movement or if a posture is to be maintained. According to Shepherd (2009), when this type of children attempt to move a limb there is an immediate relaxation of the lengthening group of muscles and control over middle ranges of movement in particular is very poor.

This type of CP was the result of injury of pyramidal and ex-pyramidal tract (Gillette's annual report, 2007). It was common for children to have symptoms that didn't correspond to any single type of cerebral palsy. There symptoms were a mix of types.

There are four main types of cerebral palsy according to movement:

According to Dietz (2010), this type of cerebral palsy typically affected the arm and hand on one side of the body, but it can also include the leg. Children with spastic hemiplegic generally walk later and on tiptoe because of tight heel tendons. The arm and leg of the affected side are frequently shorter thinner. Some children would develop an abnormal curvature of the spine (scoliosis).

In this type of cerebral palsy, muscle stiffness was predominantly in the legs and less severely affects the arms and face, although the hands may be clumsy. The word diplegia breaks down into "di" meaning two and "plegia" the latin word for weakness. Therefore, spastic diplegia means two extrimities causing weakness. Spastic diplegic CP shows a pattern similar to that of the average developing child. According to Dietz (2010) the characteristics of spastic diplegic CP include the legs often turn in and cross at the knees. Tendon reflexes are hyperactive. Toes point up. Tightness in certain leg muscle makes the legs move like arms of a scissor, in which the hips are flexed, the knees nearly touch, the feet are flexed, and the ankles turn out from the leg, causing toe walking. Children with this kind of cerebral palsy may require a walker or leg braces.

This the most severe form cerebral palsy, often associated with moderate to severe mental retardation. It caused by widespread damage to the brain or significant brain malformations. Children will often have severe stiffness in their limbs but a floppy neck. They are rarely able to walk Raj (2009).

Forfar et al., (2011) has described the following types of cerebral palsy:

Spastic hemiplegic, diplegia and ataxia type of CP. Independent living, walking, intelligence ≥ 70.

Spastic hemiplegic, diplegia and ataxia type of CP. Supported self propelled wheelchair, independent or assisted walking with brace and other orthotic devices.

Spastic quadriplegic, athetosis type of CP. Totally dependent, pushchair, and intelligence ≤50.

The various sub types of CP vary with the reporting surface, a series for Sweden noted- Hemiplegia-36.4%, Quadriplegia- 7.3%, Diaplegia-41.5%, Athetosis- 10%, Ataxic- 5% .

The relationship between the quality of life of children with cerebral palsy and their disability has been debated, and different studies have come to different conclusions regarding the impact of cerebral palsy on the well-being of these children. Although the damage does not progress over time, it can be accompanied by other co-morbidities, including seizure disorders and alterations in cognition, communication, and sensation that further impact health (Davis et al., 2011). In the past, the quality of life of children with cerebral palsy had often been related to their level of functioning, but more recent studies have shown that these children can have a good quality of life (even in comparison to children without a physical handicap) (Shelly et al., 2008). In accordance with other studies, the authors of a study on the self-reported quality of life of children with cerebral palsy found that the quality of life of these children was more influenced by social and environmental factors than by their disability (Dickenson et al., 2007).

A study on child self-report found that there is only a weak correlation between level of functioning and quality of life, and the authors of this study suggested that children with disabilities adapt to their disability. Because they do not know any other physical state in life, they often rate their quality of life as good. This is known as the disability paradox, a phenomenon in which those with disabilities can have a good quality of life with a proper understanding of their disability and strong social support and relationships (Shelly et al., 2008). Comparisons of health-related quality of life and overall quality of life and a discussion of the factors influencing quality of life will be addressed, as well as factors that can be taken into consideration while providing health care as a medical professional. It is important for health care providers to understand the child's view of his or her quality of life in order to provide individualized and appropriate care (Davis et al., 2011; Maher et al., 2008).

Contrary to what most people may believe, children with cerebral palsy often rate their quality of life as similar to that of children without a physical disability. As noted, in years past, quality of life was associated with the degree of a child's functioning. According to one study, there has been a recent change in the perception of quality of life, which was once thought to be more connected to physical functioning than wellbeing, as it is today (Davis et al., 2008). The study goes on to assert that the correlation between functioning and psychosocial health is of little consequence (Davis et al., 2008). A different study confirmed these results by finding that the perception of quality of life in children with cerebral palsy shows very few differences in self-concept and no differences in self-esteem in comparison to the ratings of children without cerebral palsy (Russo et al., 2008). Of course, this finding does not always appear to be true. A different study discovered that the relationship between degree of functioning and health-related quality of life was notable and influenced greatly by degree of physical activity (Maher et al., 2008). Another group of researchers found that only certain spheres of quality of life were impacted by physical functioning, namely physical participation and health and feelings about disability. Emotional and social quality of life were less notably linked to degree of functioning (as has been already argued) (Shelly et al., 2008). Understandably, there are differences between the questionnaires used in these various studies, which may be causing the differences in results. All studies addressed quality of life, though varied in focus between comprehensive well-being and degree of functioning. This would seem to suggest that although certain domains of emotional, as well as social, quality of life can be unaffected by disability, quality of life related to feelings about limitations and reduced physical participation is impacted by degree of functioning, as one would think. Regardless, it is important to evaluate each child individually to determine his or her degree of coping and specific quality of life.

The main factor influencing health-related quality of life that will be discussed is the pain, which one might think would be a commonly addressed issue. In a study on children with mild hemiplegic cerebral palsy (hemiplegic referring to decreased motor functioning on the side of the body controlled by the affected hemisphere), researchers found that almost half of the children interviewed (out of 107 children with an average age of 9 years old) experienced a chronic, aching pain, usually on the palsy-affected side of their body. Massage and rest were found to be the most commonly used methods of relief. However, researchers questioned why analgesics were not used more often, and suggested that this become a more prominent care consideration in the medical field (Russo et al., 2008). Another study found that while not always statistically significant, there was a lower reported quality of life in participants who had pain in the week prior to taking the survey (pain was also associated with lower self-appreciation) (Dickenson et al., 2007). In order for a child’s pain to be better controlled, this study suggested that parents need education regarding the nature of the pain their child is experiencing and the methods for reducing the pain, including the appropriate use of analgesics, such as acetaminophen. As shown, pain is not just present in children with severe cerebral palsy, but in children with mild cerebral palsy as well. There is currently research indicating that pain is not well controlled in the adult population with cerebral palsy, and it appears that this is true for the pediatric population as well (Bjornson et al., 2008). It is especially important nurses take this into consideration when caring for a child with cerebral palsy, whether in the hospital or clinic setting, and take measures to ensure adequate treatment of pain for this population in order to improve their quality of life. The presence, characteristics, and quality of the pain these children are experiencing should also be assessed more frequently by parents as well to counter it more effectively, and this should be a teaching point that healthcare providers address. A possible cause suggested for the inadequate treatment of pain was that children and parents believed this was simply part of life with cerebral palsy. Increased patient and parent education concerning this belief and the reason for treatment of pain needs to be a care priority (Bjornson et al., 2008; Dickenson et al., 2007; Russo et al., 2008).

Assessing the child’s quality of life, understanding their goals and feelings, and also seeking the parents’ input on the child’s well-being will help the healthcare provider know how best to plan care interventions that are appropriate and individualized (Dickenson et al., 2007; Vinson et al., 2010).

Russell et al. (2011) stated that there are 4 predominant motor types of CP such as spastic, ataxic, dyskinetic and mixed types of CP. Spastic CP is the commonest and accounts for 70%-75% of all cases, dyskinetic – 10% to 15% and ataxic is less than 5% of cases. Spasticity occurs when muscles have increased tone and appear stiff. This is the most common type of CP. In contrast to spastic ataxia affects balance and coordination. Children with ataxic CP may appear shaky and unsteady. In addition, dyskinesia causes a person to have involuntary movements, which generally increase when they try to move and the person can present with any combination of motor types. CP can also be classified according to the part of the body affected: quadriplegia (affects all four limbs), diplegia (affects both legs) and hemiplegia (one side of the body is affected). Mcintyre et al. (2012) stated that quadriplegic CP is the most severe form involving all four limbs, and the trunk upper limbs are more severely involved than the lower limbs.

Voluntary movements are few; vasomotor changes of the extremities are common. Most children have psuedobulbar signs with difficulties in swallowing and recurrent aspiration of food material. In hemiplegic CP, spastic hemiparesis is a unilateral paresis with upper limbs more severely affected than the lower limbs. It is seen in 56% of term infants and 17% of preterm infants. Voluntary movements are impaired with hand functions being most affected. Pincer grasp of the thumb, extension of the wrist and supination of the forearm are affected. In the lower limb, dorsiflexion and aversion of the foot are most impaired. There is increased flexor tone with hemiparetic posture, flexion at the elbow and wrist, knees and equines position of the foot. Palmer grasp may persist for many years. Sensory abnormalities in the affected limbs are common. Seizures occur in more than 50%. Visual field defects, homonymous hemianopia, cranial nerve abnormalities most commonly facial nerve palsies are seen. Spastic diplegia is associated with prematurity and low birth weight (Darsaklis et al., 2011).

Spastic cerebral palsy is the most common type of CP. Spastic cerebral palsy refers to the increased tone, or tension, in a muscle when normal muscles work in pairs. Allowing free movement in the desired direction when one group contracts and the other group relax. The flow of muscle tensions disrupted, due to complications in brain-to-nerve-to-muscle communication. Muscles affected by spastic cerebral palsy become active together and restricted in actual movement. This causes the muscles in spastic cerebral palsy patients to be constantly tense or spastic. Mild cases of spastic cerebral palsy patients may have affect only a few movements or severe cases that can affect the whole body (Darsaklis et al., 2011). The second most common type of cerebral palsy is athetoid or dyskinetic. Injuries to the basal ganglia can result in athetoid cerebral palsy, which causes involuntary muscle movements. The movements often interfere with speaking, feeding, grasping, walking and other skills requiring coordination. Now-a-days about 4% of people have cerebral palsy. Inability to activate the correct pattern of muscles during movement ataxia is defined. Injuries to the cerebellum can result in ataxic cerebral palsy, which causes poor coordination. That, in turn, affects balance, posture and controlled movements. Ataxic cerebral palsy can cause unsteadiness when walking and difficulties with motor tasks. Other type of CP is mixed CP. Injuries to multiple brain areas usually the cerebral cortex and basal ganglia can result in more than one kind of abnormal muscle tone. For example, someone could have spasticity and dystonia, or dystonia and rigidity.

Health Related Quality Of Life is an important outcome of medical treatment and has been defined as the functional effect of an illness and its consequent therapy on a patient, as perceived by that patient. In children, health related quality of life includes not only concepts of illness, functional status, mental health, and comfort, but also parental impact and family functioning. Despite the prevalence of CP, researchers are just beginning to understand the ways in which having CP can impact a child's health status and quality of life.4-7 Although several researchers have reported decreased HRQOL in children with CP, few studies have specifically addressed HRQOL across the full spectrum of children in this population. Prior studies4-6 have included a limited range of severity of illness or ages or did not use generic outcome measures to permit comparison (Vargus et al.,2005).

Caspersen, et al. (2010) defined several health-related components of physical fitness, including cardiopulmonary fitness, muscle strength and body composition. In addition, lipid profile is an important objective indicator for the risk of cardiovascular disease. We found 7 previous studies describing health-related physical fitness components in young adults with CP (12–18). Most of these studies focus on only one component, e.g. cardiopulmonary fitness, muscle strength or body composition. To our knowledge there has been no study of young adults with CP. Furthermore, the sample sizes in the previous studies were small (range 5–19), and the study groups were heterogeneous with regard to level of motor functioning. Moreover, most of the studies were old with 4 of the 7 studies being over 20 years old. The approach to paediatric rehabilitation has changed and developed over the years, and this may have influenced current physical fitness levels in young with CP. The goal of the present study was therefore to describe in detail the health-related physical fitness of spastic CP aged (Nooijen et al., 2014).

Chronic illnesses have been shown to have negative impact on the quality of life in adult populations, but with little focus on children, especially those from developing countries. A study that reveals the impact of chronic illness on the quality of life of children is important, as it will provide information to enable better management of this part of the population. In children, health-related quality of life includes not only concepts of illness, functional status, mental health and comfort, but also parental impact and family functioning. Despite the wide-spread prevalence of cerebral palsy, researchers are just beginning to focus on its impact on children's health status and quality of life (Kennes, 2009). There are increasing data from the Western countries, with less focus on the developing countries where there could be less sophisticated gynaecological and paediatric care (Tella et al., 2011).

The oral manifestations associated with CP are changes in the structure of the oro facial region, development of para functional habits, which include swallowing and drooling problems; the affected individual also experience difficulties in maintaining acceptable levels of oral hygiene . A better understanding of how the various general health-related issues affect the daily lives of CP children by using health-related quality of life (HRQoL) assessments has proven to be of value to health care workers (Du et al., 2010).

In CP, several authors have reported a reduction in functional skills, such as walking, at an earlier age than would be expected due to normal ageing. Gross motor function, fatigue and musculoskeletal pain, referred to in this article as "pain," are reported as the main causes of reduced functional skills (1, 4–7). Studies on pain intensity, duration, frequency, and the most common pain sites are difficult to compare because of differences in categorizations, definitions of chronic pain, and the samples of the CP population.

In addition to the disturbances of movement and posture including spasticity, muscle weakness and reduced coordination, common impairments of children with CP include disturbances of sensation, perception, cognition, communication, behavior, epilepsy, and secondary musculoskeletal problems (Rosenbaum, et al., 2009). Reduced activity levels and participation restrictions due to these impairments may lead to a reduced quality of life (QOL), compared to their typically developing peers (Varni et al., 2009).

The specific factors influencing the well-being of both young children and adolescents with cerebral palsy will now be discussed. Younger children with cerebral palsy tend to self-report a higher quality of life than adolescents with the same physical disability. This higher quality of life rating can be in part explained through the disability paradox, in which individuals with a disability can report a good quality of life because their disability is all that they have ever known and they have come to accept it. This is especially true in children with strong relationships with family and friends (Shelly et al., 2008). Although this phenomenon can certainly be true in adolescents as well, due to their increased awareness of self and peers, they may begin to struggle more with acceptance of the disability while in their teen years (Bjornson et al., 2008). Interestingly, in a study comparing the self-generated domains relating to quality of life for children ages 6-12 with and without cerebral palsy, the domain pertaining to physical health and needs was identified as influential more often in children without a disability than in children with cerebral palsy. Similarly, the domain of physical activity was identified as significant more often by children with cerebral palsy than by children with typical development. This finding suggests that children tend to take certain spheres of their quality of life, such as physical functioning, for granted, leading to differences in perceived importance among various domains (Vinson et al, 2010). For younger children, their disability was found to be unrelated to their level of quality of life in six categories pertaining to finances, self-perception, social and psychological well-being, school atmosphere, and social acceptance (Dickenson et al., 2009). Their quality of life was found to affect physical and emotional well-being and relationships with parents when the disability caused trouble walking, cognitive impairment, and speech difficulty respectively (Dickenson et al., 2009). This study found there was no strong relationship between emotional health and the degree of impairment, which would seem to suggest that children with cerebral palsy should be treated with the same considerations in this area as children without physical disabilities. Although overall quality of life may not be strongly correlated to degree of functioning, according to the Livingston et al. study, studies have shown that health-related quality of life is lower in those with decreased motor functioning (Vinson et al., 2010).

When determining how to best provide care interventions for young children with disabilities, it is important to assess what activities the child is motivated to perform. The authors of a study, conducted on the leisure activities of children ages 6-12 with cerebral palsy, state that parents should encourage participation in recreational activities because this is important in promoting health and engagement with peers, developing skills, and increasing enjoyment of life in general (Majnemer et al., 2009).

The King et al. study from 2002 (Almasri et al., 2011) promotes increased participation in social and leisure activities as the primary goal of rehabilitation for children with cerebral palsy. The Majnemer et al. study found that children preferred social activities over recreation and tasks related to self-improvement (2009). Findings indicate a higher rate of desire to participate in an activity (whether physical or social) than a rate of actual participation among children with cerebral palsy. In light of this finding, encouraging a child to overcome their fears and failures and teaching them to learn from their failures will help ensure a higher rate of actual participation (Majnemer et al., 2009). Identifying those obstacles, whether personal or environmental, will help those providing rehabilitation services foster intrinsic motivation in children (Majnemer et al., 2009).

CHAPTER-III METHODOLOGY

3.1 Study Design:

Quantitative research design focuses on descriptive study. Jack and Norman (2007) suggested that; Quantitative data are obtained when the variable being studied is measured along a scale that indicates how much of the variable is present. Quantitative data are reported in terms of scores. Higher scores indicate that more of the variable (Such as weight, academic ability, self-esteem, or interest in mathematics) is present than do lower scores. Descriptive studies are those data that can describe, organize, and summarize data.

A cross sectional survey collects information from a sample that has been drawn from a predetermined population (Jack and Norman, 2007). The study was conducted through cross sectional study design that represent the whole population of Children with cerebral palsy. Levin (2006) stated that Cross-sectional studies are carried out at one time point or over a short period.

This study was conducted using cross sectional prospective survey under a quantitative study design. Cross sectional study design was chosen to meet the study aim as an effective way to collect data.

3.2 Study site:

Data was collected from the outdoor and indoor Paediatric physiotherapy unit of the centre for the rehabilitation of the paralysed and William and Marie Taylor School in Savar.

3.3 Study duration

Time schedule for thesis work, Six Months from February 2016 to August 2016.

3.4 Study Population:

Children with Cerebral Palsy.

3.5 Sample size:

Sample a group of subjects was selected from population, who are used in a piece of research. A sample is a smaller group taken from the population. Sometimes the sample size may be big and sometimes it may be small, depending on the population and the characteristics of the study.

The equation of sample size calculation are given below

$$n = \left\{ \frac{Z\left(1 - \frac{\alpha}{2}\right)}{d} \right\}^2 \times pq$$

Here,

$Z\ (1- \frac{\alpha}{2}) = 1.96$

p= Prevalence of cerebral palsy in Bangladesh= 6.1%= 0.61 (Tabib, 2009)

q = 1-P

=1-0.61

=0.39

d=0.05

The actual sample size for this study was calculated as 353, but as the study performed as a part of academic research project and there were some limitation, so that 100 cerebral palsy children was taken as the sample of this study from Paediatric unit and William and Marie Taylor school of CRP at Savar.

3.6 Inclusion criteria:

1. Children with a diagnosis of cerebral palsy.
2. Age range between 3-12 years.
3. Both boys and girls are included (Dobhal et al, 2014).
4. Receiving regular (at least 1 visit for 1 week) physical therapy/occupational therapy.

3.7 Exclusion criteria:

1. Non-availability of the primary caregiver.
2. Presence of other chronic illnesses not typically associated with cerebral palsy.
3. Families having another child with cerebral palsy, autism or intellectual disability (Dobhal et al, 2014).
4. Severe spasticity according to Modified Ashworth scale among Cp are excluded.

Modified Ashworth Scale for grading Spasticity

Grade	Description
0	No increase in muscle tone
1	Slight increase in muscle tone, manifested by a catch or release or minimal resistance at the end of the ROM when the affected part is moved in flexion or extension
1+	Slight increase in muscle tone, manifested by a catch or release or minimal resistance throughout remainder (less than half) of the ROM
2	More marked increase in muscle in muscle tone through most of the ROM, but affected part is easily moved
3	Considerable increase in muscle tone, passive movement difficult
4	Affected part is rigid in flexion and extension

3.8 Sampling technique:

Findings the appropriate number and type of people take part in the study is called "sampling". The study was conducted by using the purposive sampling methods due to the time limitation and as it was one of the easiest, cheapest and quicker method of sample selection. The researcher was used this procedure, because getting of those samples whose criteria would concerned with the study purpose.

3.9 Data Collection procedure

3.9.1 Data collection instrument

A structured Life Assessment Questionnaire (LAQ) and demographic information chart was using as a data collection instrument. In that time some other necessary materials were used like pen, pencil, and white paper and clip board. The English questionnaires was converted into Bengali to ask the participants during interviews. Researcher have taken permission from each volunteer participant by using a written consent form in Bengali & English.

Life Assessment Questionnaire

LAQ-CP questionnaire evaluates the impact of disability in children with CP and their families. It has 46items, organized into six dimensions: physical independence, mobility, clinical burden, schooling, economic burden, and social integration. Based on scores in each item, dimensional scores and a final standard score, known as Lifestyle Assessment Score (LAS) is obtained. These are expressed as a percentage score. The classification of the HRQOL according to LAS is as follows: Good (<30%); mildly-affected (30-50%); moderately-affected (51-70%); and severely-affected (>70%) (PC et al., 2000).

The LAQ-CP is a 46 items questionnaire, organized into 6 dimensions through the application of multi-dimensional scaling. Dimensions are named to reflect elements of the International Classification of Impairment, Disabilities and Handicaps (Wood, 2009).

The resulting dimensional structure identified six groups of items, which are named by ourselves to reflect elements of the ICIDH classification system. The dimensions are 'clinical burden' (reflecting the increased burden to the family of the need for numerous contacts with professionals/services) emerges as a major dimension within the structure. The ICIDH dimensions o 'occupation' and 'economic self-sufficiency' are represented by dimensions named ‘schooling’ and ‘economic burden’. The other dimensions are ‘Physical independence’, ‘Mobility’, ‘Social integration’. It must be stressed that the LAQ-CP is only validated as a descriptive/discriminative tool. It is able to discern variations between individual children at a given point in time.

3.9.2 Procedure of data collection

At very beginning researcher clarified that the participant had the right to refuse the answer of any question during completing questionnaire. They can withdraw from the study at any time. Researcher also clarifies to all participants about the aim of the study. Participants were ensuring that any personal information was not be published anywhere. Researcher took permission from each volunteer participant by using a written consent form. After getting consent from the participants, standard questionnaire was using to identify the complaint and collect demographic information. Questions were asking according to the Bangla format.

For conducting the interview, the researcher conducts a face to face interview and was asking questions. Physical environment was consider strictly. Stimuli that can distract interviewee was removed to ensure adequate attention of interview. Interviewee was ask questions alone as much as possible with consent as sometimes close relatives can guide answer for them. The researcher built report and clarified questions during the interview. Face to face interviews were the most effective way to get full cooperation of the participant in a survey (Fraenkel & Wallen 2009, p. 436). Face to face interviews were also effective to describe characteristics of a population. Face to face interview was used to find specific data which describes the population descriptively during discussion. According to the participants understanding level, sometimes the questions were described in the native language so that the patients can understand the questions perfectly and answer accurately. All the data were collected by the researcher own to avoid the errors.

3.10 Data analysis

Descriptive statistics are used to analyze data. Descriptive statistics refers methods of describing a set of results in terms of their most interesting characteristics (Hicks 2009, p. 284). Data was analyzed with the software named Statistical Package for the Social Science (SPSS) version 16.0. The variables were labeled in a list and the researcher established a computer based data definition record file that consist of a list of variables in order. The researcher put the name of the variables in the variable view of SPSS and defined the types, values, decimal, label alignment and measurement level of data. The next step was cleaning new data files to check the inputted data set to ensure that all data has been accurately transcribed from the questionnaire sheet to the SPSS data view. Then the raw data was ready for analysis in SPSS. Data was analyzed by descriptive statistics and calculated as percentages and presented by using table, bar graph, pie charts etc. Microsoft office Excel 2010 was used to decorating the bar graph and pie charts. The result of this study was consisted of quantitative data. By this study a lot of information was collected.

3.11 Ethical Consideration

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. The proposal of the dissertation including methodology was presented to the Institutional Review Board (IRB) of Bangladesh Health Professions Institute (BHPI). Again before the beginning of the data collection, researcher has obtained the permission from the concerned authorities ensuring the safety of the participants. The researcher strictly maintained the confidentiality regarding participant's condition and treatments. The researcher obtained consent to participate from every subject. A signed informed consent form was received from each participant. The participants had informed that they have the right to meet with outdoor doctor if they think that the treatments were not enough to control condition or if the condition became worsen. The rigorous manner was maintained to conduct study. The study was conducted in a clean and systematic way. During data collection it was ensured that participants were not influenced by data collector.

The researcher was obtaining consent to participate from every subject. A signed informed consent form was received from each participant. The participants were informed that they have the right to meet with outdoor doctor if they think that the treatment is not enough to control the condition or if the conditions become worsen. The participants was informed that they are completely free to decline answering any question during the study and are free to withdraw their consent and terminate participation at any time. Withdrawal of participation from the study will not affect their treatment in the physiotherapy department and they still will get the same facilities. Every subject has the opportunity to discuss their problem with the senior authority or administration of CRP and have any questioned answer to their satisfaction.

CHAPTER-IV RESULTS

Socio-demographic Information

An exploratory data analysis was conducted among 100 children to have a preliminary idea about the trends of data. The mean age of the respondents was 7.8 years with a standard deviation of 2.93 (table 1). Majority of the respondents (52%) were 8 to 12 years old followed by 3 to 7 years old (48%).

Table-1 Characteristics of children age

	Total, N=100
Age (mean ± SD)	7.8±2.93
3-7 Years	48 (48%)
8-12 Years	52 (52%)

4.1 Children gender

Children in the study were aged between 3 to 12.Analysis shows that among this 66% boys and 34% girls.

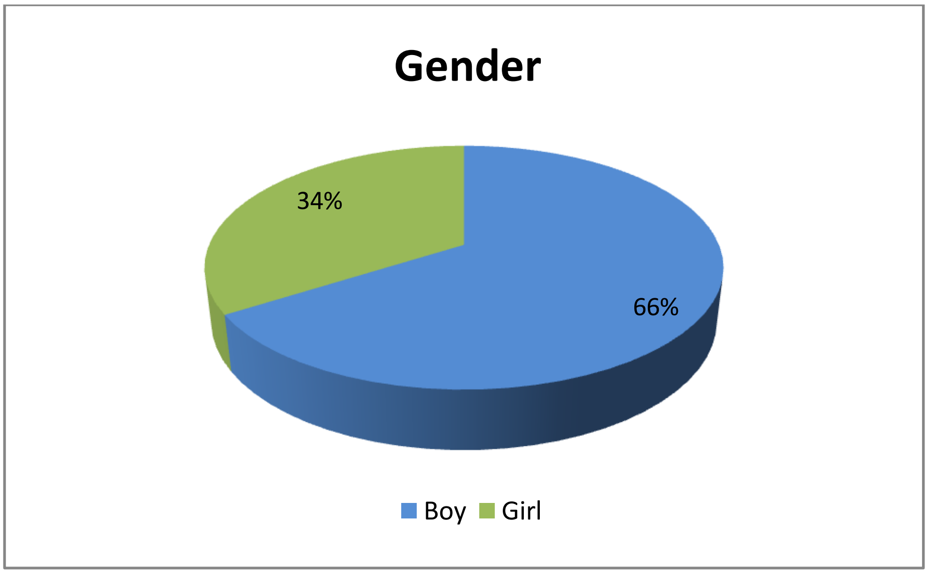


Fig-1: Gender

4.2 Mothers education

Participants number 100. After completing analysis the results shows that 37% children's mother education level SSC, 26% are HSC completed, 18% primary, 9% Signature, 4% Illiterate, 3% Degree, 3% Masters Level.

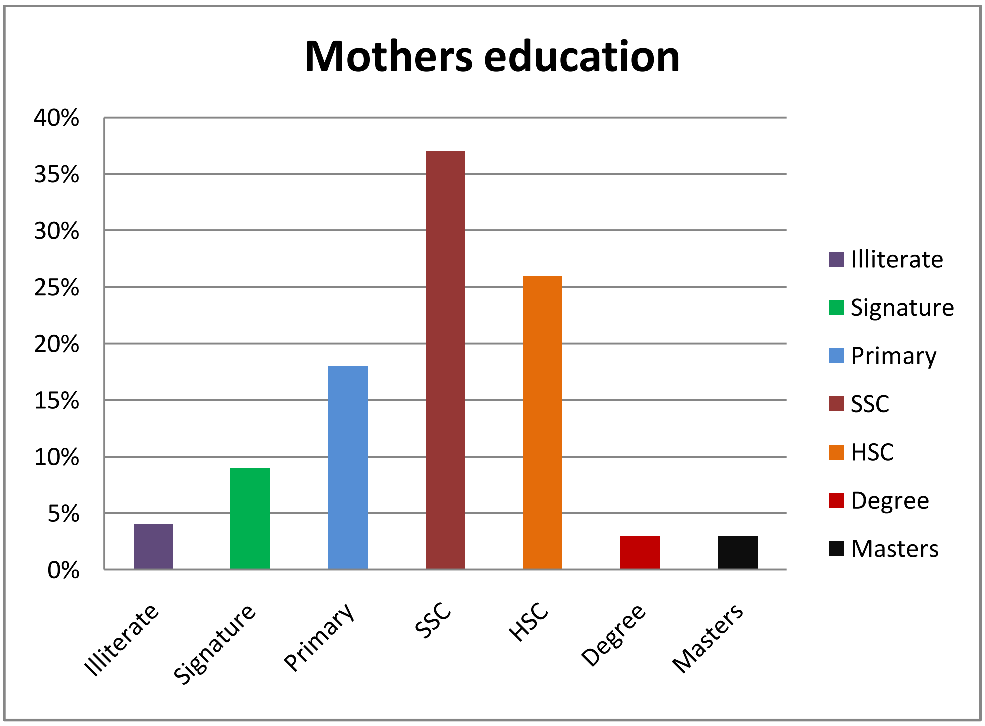


Fig-2: Mothers educational level

4.3 Mothers age during child birth

Analysis shows that among 100 numbers of participants 62% mothers age are 18-22 years during child birth, 27% mothers 23-26 years, 7% mothers 27-30 years and 4% mothers 31-35 years during child birth.

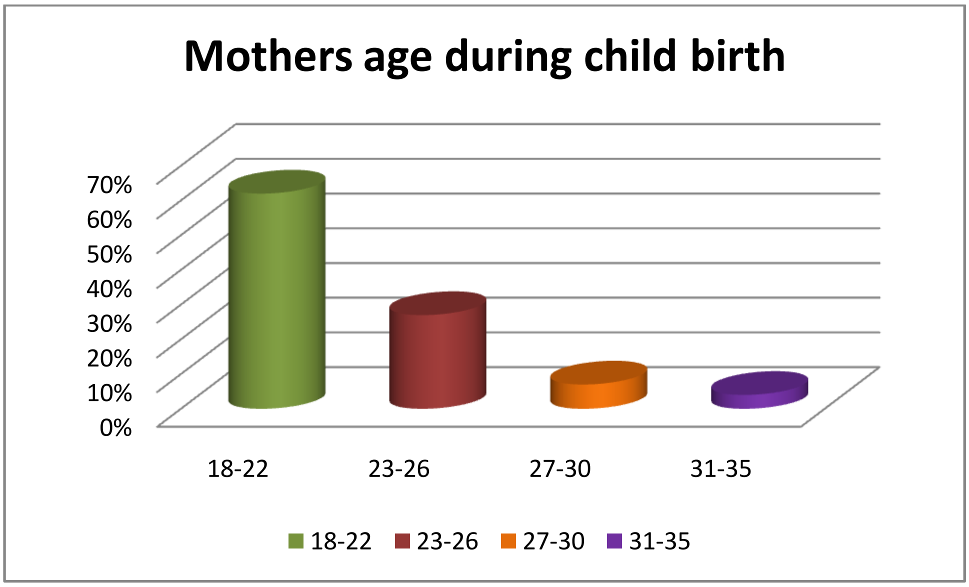


Fig-4: Mothers age during child birth

4.4 Child diseases after birth

According to analysis among 100 children 24% children have suffered from dehydration, 21% Jaundice, 10% pneumonia, 5% seizure and 40% children did not have all this.

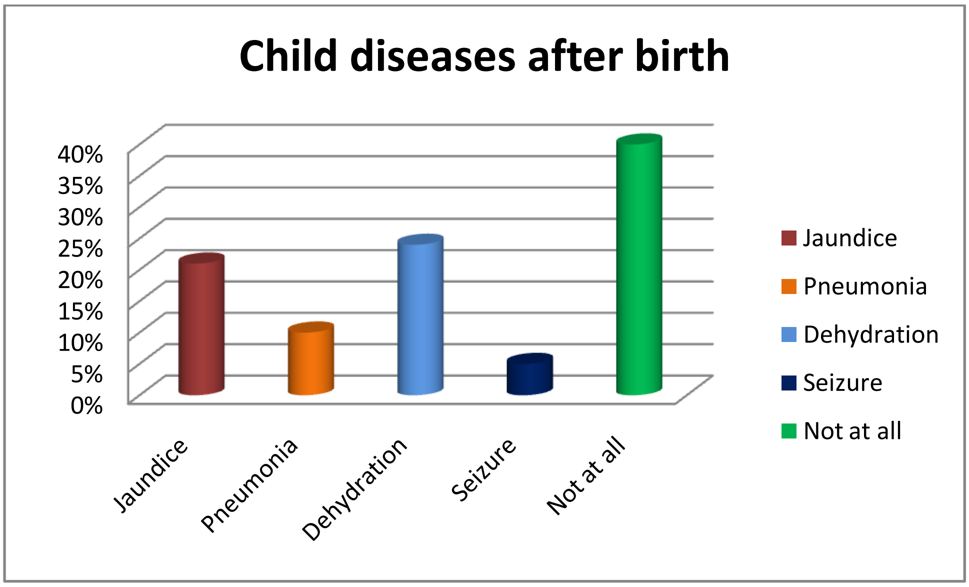


Fig-5: Child diseases after birth

4.5 During child birth was there any incidence

After completing analysis the result shows that 56% children have occurred Birth asphyxia, 44% children have occurred Birth injury during the time of birth.

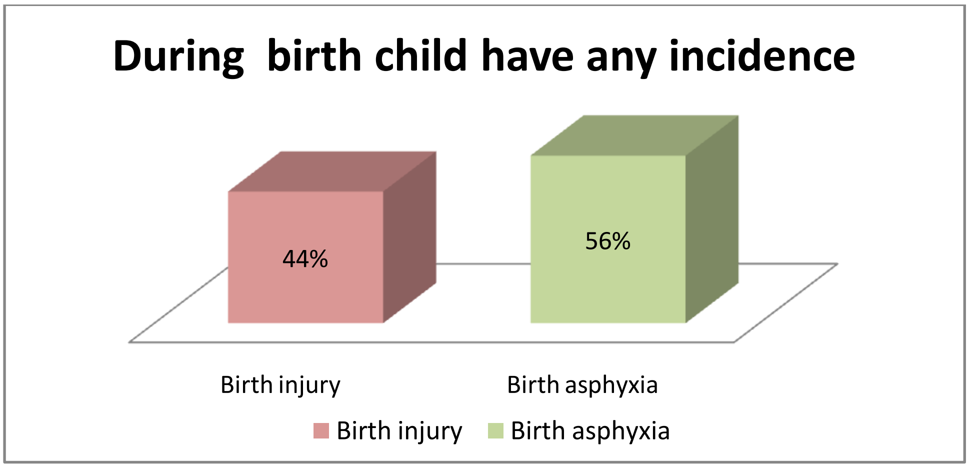


Fig-6: During child birth child have any incidence

Table-2: Life Assessment Questionnaire

Dimensions	Mean score
Mobility	2.37 (1- 3.44)
Schooling	2.15 (.33-3.67)
Physical Independence	1.84 (.50-3.75)
Social Integration	1.78 (.75-3.13)
Economic burden	1.46 (.14-2.86)
Clinical burden	1.34 (.27-2.55)

According to analysis the mean score of mobility was 2.37.That means highest number of 2.37 children affected in mobility. Mobility includes opening door, picking an object, carrying a drink, number of rooms, children entered unassisted, getting in and out of car, longer outing excluding school. For those activities maximum children had needed maximum to moderate assistance. The minimum to maximum range was (1-3.44). The mean score of schooling was 2.15. That means 2.15 children affected in schooling. Schooling includes type of school, time of attendance, distance between home and school. For those activities children had needed maximum to moderate assistance. The minimum to maximum range was (.33-3.67). Analysis shows that the mean score of physical independence is 1.84. That means 1.84 children moderately affected in physical independence. It includes cleaning hand, eating bowl of food, buttoning, putting shirt, toileting, climbing stair, need help at night and need lift. For those activities children had needed moderate to minimum support. Minimum to maximum range was (.50-3.75). The mean score of social integration 1.78 means 1.78 children are affected in social integration. It includes friends meet, helpful family, supportive and understanding neighbor, family restriction, organizing holiday. For those activities child needed minimum to moderate assistance. Minimum to maximum rage was (.75-3.13). Mean score of economic burden 1.46 means 1.46 children are affected in economic burden. It includes special food, money spent in home modification, help from organization, and job change for children. For these activities children had needed moderate to minimum help. The mean score 1.34 of clinical burden means 1.34 children affected in clinical burden. It includes number of consulting doctor, number of taking medicine, duration of staying hospital, number of occurring operation, need of special equipment or plasters. For those activities children needed moderate to minimum help.

According to LAQ after completing analysis over 100 children we found that the value of clinical burden is 144.86. It is the lowest number than other dimensions. So it focused that in this section children required minimum support to complete their task. After giving minimum support children can perform activities. The value is gradually increases in other dimensions according to severity. Economic burden is 144.86, Social integration is 172, Physical independence is 181.92, Schooling is 222, Mobility is 236.11. It is clear that the highest value is 236 in Mobility. In this section children need maximum support to do their task.

As mobility is the highest value so for the analysis value the result was divided into two category by age that is 3-7 is group A another is 8-12 that is group B. After doing analysis it was shown that the mean value of group A is 2.55 and group B is 2.2. It indicates group A is more affected than group B that means 3-7 years children were more affected than 8-12 years in mobility.

In Physical independence the mean value of group A is 1.8 and group B is 1.65 that means 3-7 years children were more affected than 8-12 years old children in physical independence. In Clinical burden the mean value of group A is 1.49 and group B is 1.28 that means 3-7 years children were more affected than 8-12 years old. In Schooling the mean value of group A is 1.72 and group B is 2.35 that means 8-12 years children were more affected than 3-7 years children in schooling. In economic burden the mean value of group A is 1.39 and group B is 1.49 that means 8-12 years children were more affected than 3-7 years children in economic burden. In social integration the mean value of group A is 1.75 and group B is 1.61 that means 3-7 years children were more affected than 8-12 years children in economic burden.

CHAPTER-V DISCUSSION

The study was planned to see the quality of life of cerebral palsy children among 3-12 years. After analysis shows that most of the children under this study maximum age is 12 and minimum age is 7. Mother's age is important for child birth. Because under 17 and over 30 years mothers are high risk for abnormal baby birth. In this study maximum mothers age are 17-20. Diseases after birth like Jaundice, Pneumonia, Dehydration and Seizure are important for children birth. Over this study most of the children suffered from dehydration, Pneumonia, Jaundice, Seizure after birth which are responsible for CP child birth. Most of the children have occurred birth injury and birth asphyxia during birth. These are basic points to analyze the CP child birth which is related to this study. After analysis the quality of a CP children most of them are affected in Mobility like opening door, carrying a drink, walking unassisted, picking an object. In those activities most of the children need assistance that means they do not complete these by moderate or without assistance.

Same as schooling children also affected more like type of school, duration of school attendance, distance between home and school in those activities children do not complete daily task without support. Moderate support is needed for them. One of the important topic is physical independence that includes duration of consulting doctor, time of staying hospital, number of supportive device or plaster, number of operation, consulting physiotherapist or psychiatrist which are primary point to measure a CP child quality of life. After completing this study it indicates that most of the children completed their daily physical activities by moderate to minimum support. In the present study, HRQOL was moderately to severely affected in two-third of children with CP, and their families. The physical independence, mobility and social integration dimensions of HRQOL were much more severely affected than the clinical burden, economic burden and schooling dimensions. (Singhi, 2010). Social integration, clinical burden, economic burden also important for quality of life measurement. But in this study children need minimum to moderate support for accomplish these activities. A study from Malaysia (Yee and Wong, 2009) using the same questionnaire reported good HRQOL in the majority, and only 11.1% having severely-affected HRQOL. The better QOL in this study could have been due to difference in severity, psychosocial factors and availability of the health care services.

Other studies done worldwide show that HRQOL is adversely affected in children with CP.

A large cohort of children with CP was stratified into 5 levels of severity, and a clear relation between severity of CP and HRQOL was shown. Most of the effects were related to physical functioning issues and impact on the parents or caregivers. Psychosocial HRQOL was better than physical HRQOL. The relations among increasing number of medical problems, severity of CP, and reduced HRQOL were not surprising. A significant brain insult resulting in severe symptoms of CP is also likely to cause other medical issues, such as mental retardation or seizures. (Adams and J. 2005)

In the studied group of parents of children with cerebral palsy, less than half described their quality of life as good and 40% as "neither good nor bad". In the group of parents of CP children, nearly ¼ described their quality of life is not so good.

In the analyzed group of parents of children with cerebral palsy, less than half were satisfied with their own health, 1/4 stated that they are "neither satisfied nor dissatisfied", and most of them were dissatisfied. Approximately very few of the parents. Of CP children were satisfied with their own health, and others were dissatisfied.

Comparing the psychological domain of parents of children with cerebral palsy and parents of healthy children, the biggest differences were in the assessment of enjoyment of life, the meaning of life, acceptance of physical appearance and experience of negative feelings. Minor differences between the two groups can be observed in the ability to concentrate and the feeling of satisfaction with self.

The appearance of a disabled child usually becomes a factor that disrupts the hitherto functioning of the family. Hence, the first reactions of parents after a disability diagnosis express their confusion, despair, and irrational hopes. The dominating reactions are sense of injustice, resentment against fate, blaming each other, and searching for a negation of the diagnosis or methods for quick elimination of the disease. Children with disabilities require continuous visits to specialist clinics, often long hours of rehabilitation exercises, and specialist consultations.

In the studied group, the most numerous group consisted of parents of children that walk with limitations, using an orthopedic device and a rehabilitation wheelchair. An analysis of the study results revealed that the quality of life of parents of children with cerebral palsy was significantly lower compared with the group of parents of healthy children. Physical health functioning, mental state, social relationships, and environment were significantly higher in the group of parents of healthy children. 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. Our results are consistent with the findings of other authors. (Okurowska et al., 2011)

Studies have shown that the severity of cognitive and communication ability increases the difficulty for a child to express his/her feelings. In this study, the severity of CP and communication ability had a greatest negative impact on the physical symptoms and functional limitations domains.

This study was carried out to evaluate the Health-Related Quality of Life (HRQoL) of children with cerebral palsy. It evaluated variables that impact health status and quality of life, and determine the severity of motor disability in children with cerebral palsy. The higher incidence of cerebral palsy among males in this study shows that more male children are susceptible to non-progressive injury to the brain at infancy. This result corroborates those of previous studies, that male children have higher incidence of cerebral palsy (Johnson, 2002). The fact that the number of reported medical problems and deformities were higher in children with more severe cerebral palsy shows that the prevalence of common medical problems increase with an increasing severity of motor disability. This has also been previously observed (Adams, 2005). The significant association between severity of cerebral palsy and physical disability shows that severity of disability is associated with poorer general health and physical disability. This finding is in agreement with several previous studies which concluded that the health-related quality of life of children with cerebral palsy has an interdependent relationship with their functional status (Wake et al, 2003; Adams, 2005).

The influence of severity of cerebral palsy on health-related quality of life among children with cerebral palsy might be due to the subjects physical condition interfering with their personal and social activities. This may indicate limitations in school work, social activities, and friendships. This observation is in agreement with the report of some previous authors, that there is significant association between social activity and severity of cerebral palsy among children with cerebral palsy (Wake et al, 2003; Adams, 2005).

5.1 Limitation

Time and resources were limited which have a great deal of impact on the study and affect the result of the study to generalize for wider population.

The small sample size may constitute a limitation as to the general ability of findings from this study.

LAQ-CP has limitations of not addressing some of the domains of QOL, as it specifically measures the impact of disability on the life of children with cerebral palsy and their families.

Being a single-center study, and including a uniform population of children receiving regular therapy, findings may not be representative of the general population.

Our study relied on parental report, due to lack of a self-report version of the questionnaire; accurate measurement of HRQOL may have been compromised.

CHAPTER-VI CONCLUSION AND RECOMMENDATION

6.1 Conclusion

To conclude, HRQOL is significantly affected in majority of children with cerebral palsy. Measurement of HRQOL should be used with other forms of assessment, to indicate areas in which a person is most affected and help the practitioner in making appropriate decisions for patient care.

Although the diagnosis of cerebral palsy can have devastating effects on a family as a whole, the quality of life of the family members can be high if the proper support and perspective, coping strategies, and individualized family care are present.

The present finding indicates that cerebral palsy has a negative impact on health status and quality of life of children with cerebral palsy, as reported by the respondent parents. Children with cerebral palsy have a reduced HRQoL, and the degree to which it is reduced is directly related to the age and severity of the cerebral palsy. Increasing age and severity of the cerebral palsy have a negative impact on physical function, social role/behavior, parenting impact (time/emotion), children's health and their psychosocial function.

6.2 Recommendation

In future larger sample size is recommended to assess the Quality of life of cerebral palsy children.

Children, if able, should give a report of their own quality of life, sharing the activities they would like to participate in and the nature of their pain so that appropriate care can be given.

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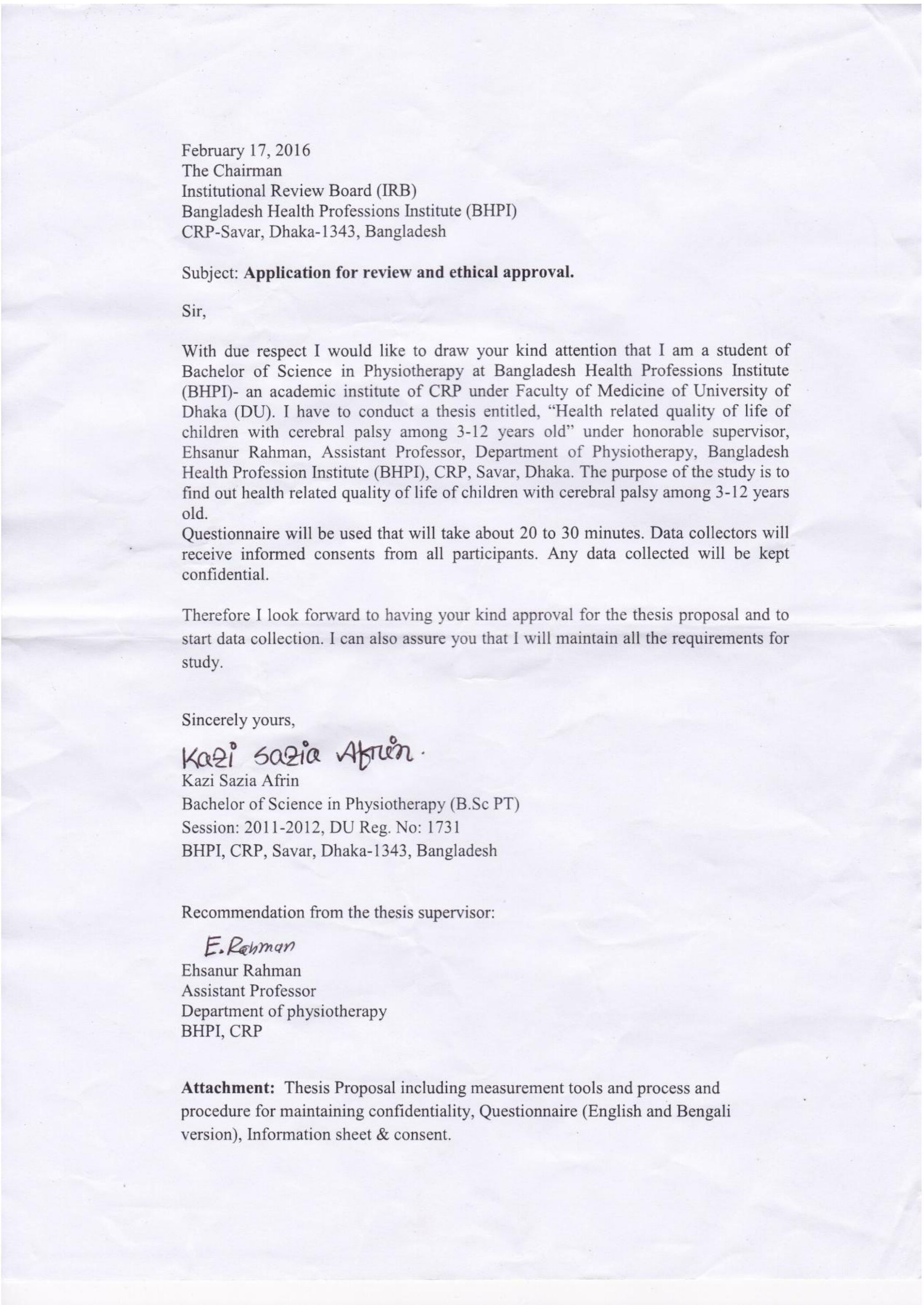
APPENDIX



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

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

Sir,

With due respect I would like to draw your kind attention that I am a student of Bachelor of Science in Physiotherapy at Bangladesh Health Professions Institute (BHPI)- an academic institute of CRP under Faculty of Medicine of University of Dhaka (DU). I have to conduct a thesis entitled, "Health related quality of life of children with cerebral palsy among 3-12 years old" under honorable supervisor, Ehsanur Rahman, Assistant Professor, Department of Physiotherapy, Bangladesh Health Profession Institute (BHPI), CRP, Savar, Dhaka. The purpose of the study is to find out health related quality of life of children with cerebral palsy among 3-12 years old.

Questionnaire will be used that will take about 20 to 30 minutes. Data collectors will receive informed consents from all participants. Any data collected will be kept confidential.

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

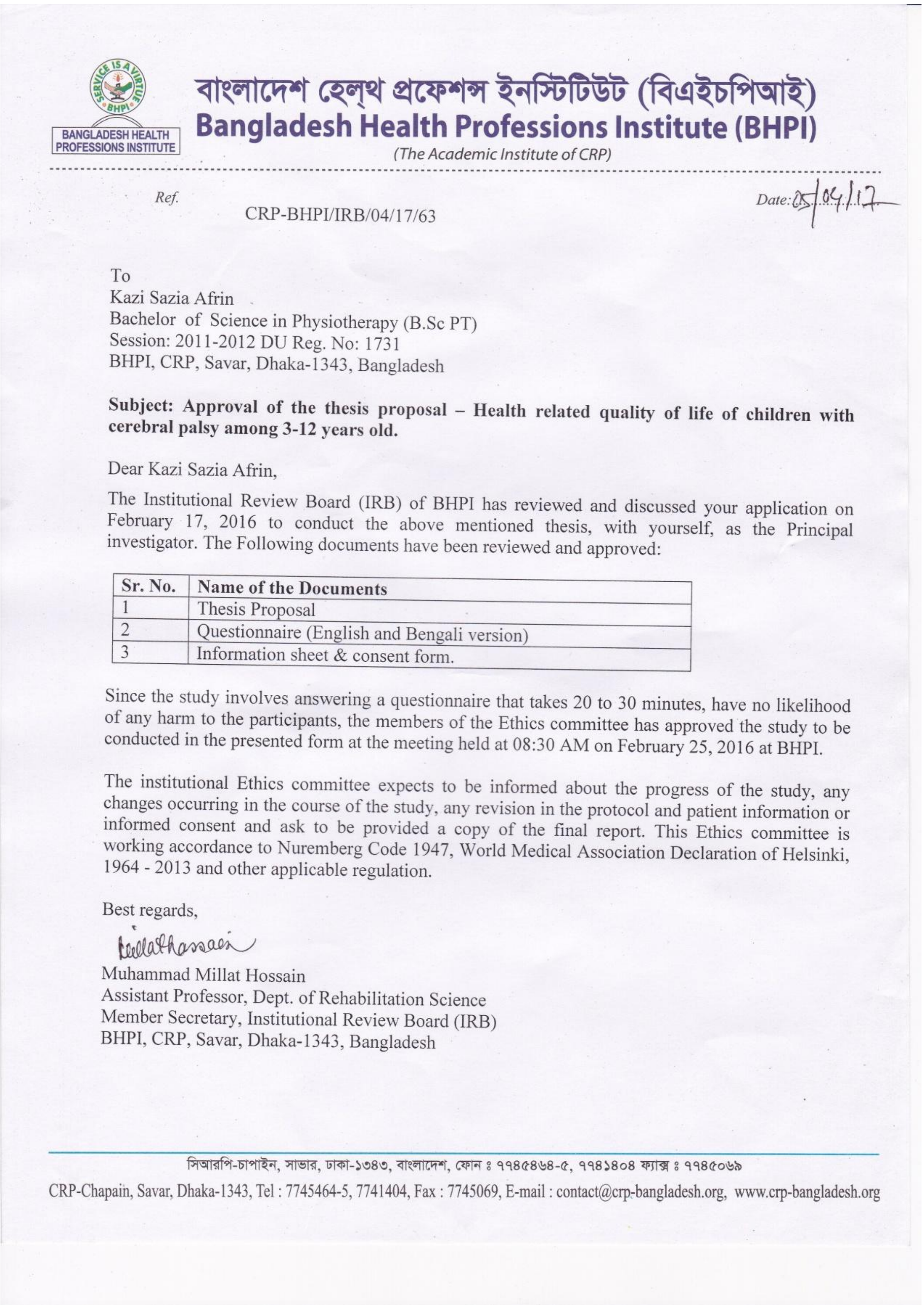
Sincerely yours,

Kazi Sazia Afrin.
Kazi Sazia Afrin
Bachelor of Science in Physiotherapy (B.Sc PT)
Session: 2011-2012, DU Reg. No: 1731
BHPI, CRP, Savar, Dhaka-1343, Bangladesh

Recommendation from the thesis supervisor:

E. Rahman
Ehsanur Rahman
Assistant Professor
Department of physiotherapy
BHPI, CRP

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



SERVICE IS A VIRTUE
BHPI
BANGLADESH HEALTH PROFESSIONS INSTITUTE

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

Ref. CRP-BHPI/IRB/04/17/63

Date: 05/04/17

To
Kazi Sazia Afrin
Bachelor of Science in Physiotherapy (B.Sc PT)
Session: 2011-2012 DU Reg. No: 1731
BHPI, CRP, Savar, Dhaka-1343, Bangladesh

Subject: Approval of the thesis proposal – Health related quality of life of children with cerebral palsy among 3-12 years old.

Dear Kazi Sazia Afrin,

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

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

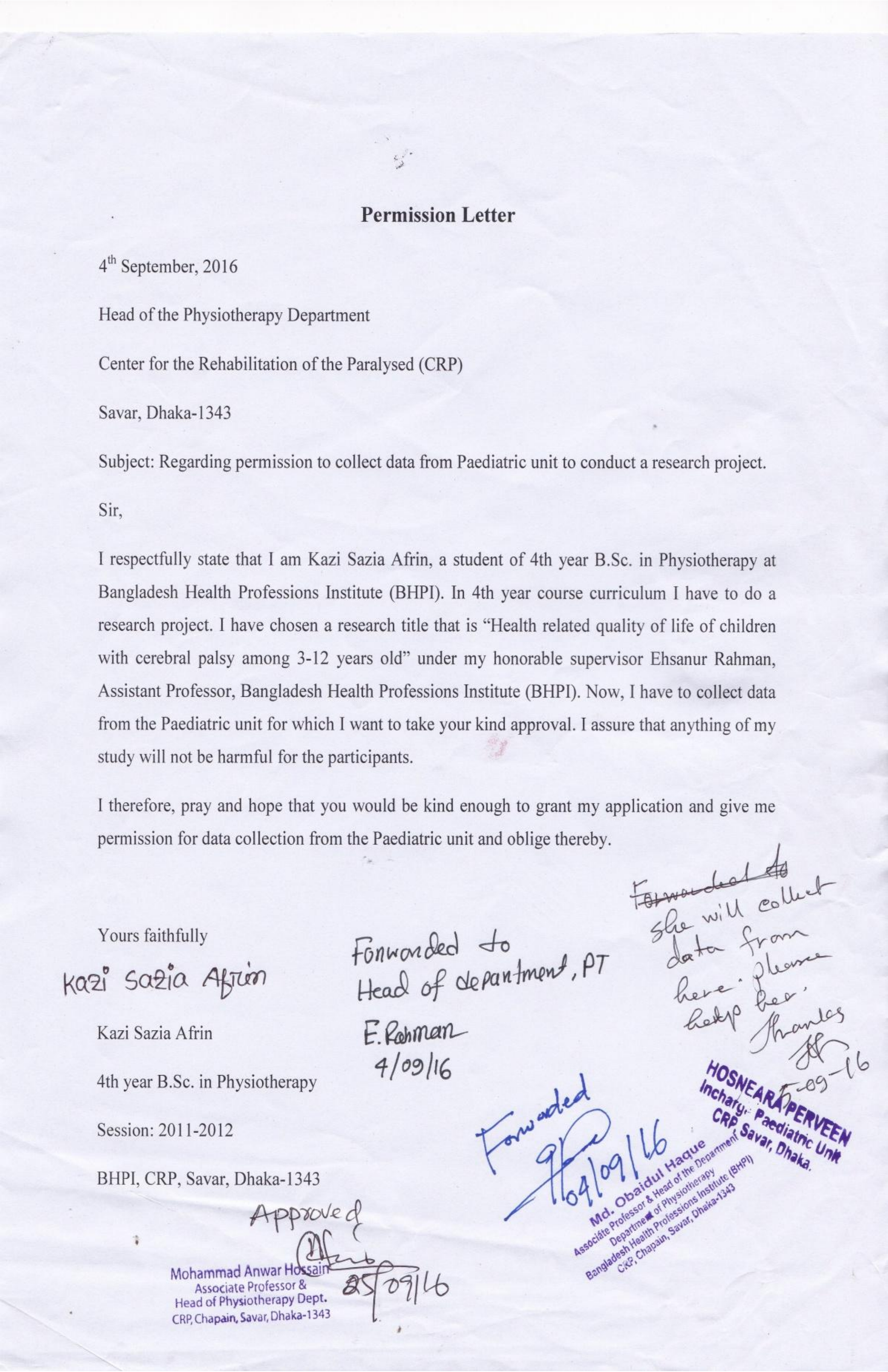
Since the study involves answering a questionnaire that takes 20 to 30 minutes, have no likelihood of any harm to the participants, the members of the Ethics committee has approved the study to be conducted in the presented form at the meeting held at 08:30 AM on February 25, 2016 at BHPI.

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

Best regards,

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

সিআরপি-চাপাইন, সাভার, 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



Permission Letter

4th September, 2016

Head of the Physiotherapy Department

Center for the Rehabilitation of the Paralysed (CRP)

Savar, Dhaka-1343

Subject: Regarding permission to collect data from Paediatric unit to conduct a research project.

Sir,

I respectfully state that I am Kazi Sazia Afrin, a student of 4th year B.Sc. in Physiotherapy at Bangladesh Health Professions Institute (BHPI). In 4th year course curriculum I have to do a research project. I have chosen a research title that is "Health related quality of life of children with cerebral palsy among 3-12 years old" under my honorable supervisor Ehsanur Rahman, Assistant Professor, Bangladesh Health Professions Institute (BHPI). Now, I have to collect data from the Paediatric unit for which I want to take your kind approval. I assure that anything of my study will not be harmful for the participants.

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

Yours faithfully

Kazi Sazia Afrin

Kazi Sazia Afrin

4th year B.Sc. in Physiotherapy

Session: 2011-2012

BHPI, CRP, Savar, Dhaka-1343

Forwarded to
Head of department, PT
E.Rahman
4/09/16

~~Forwarded to~~
She will collect
data from
here. please
help her.
Thanks
5-09-16

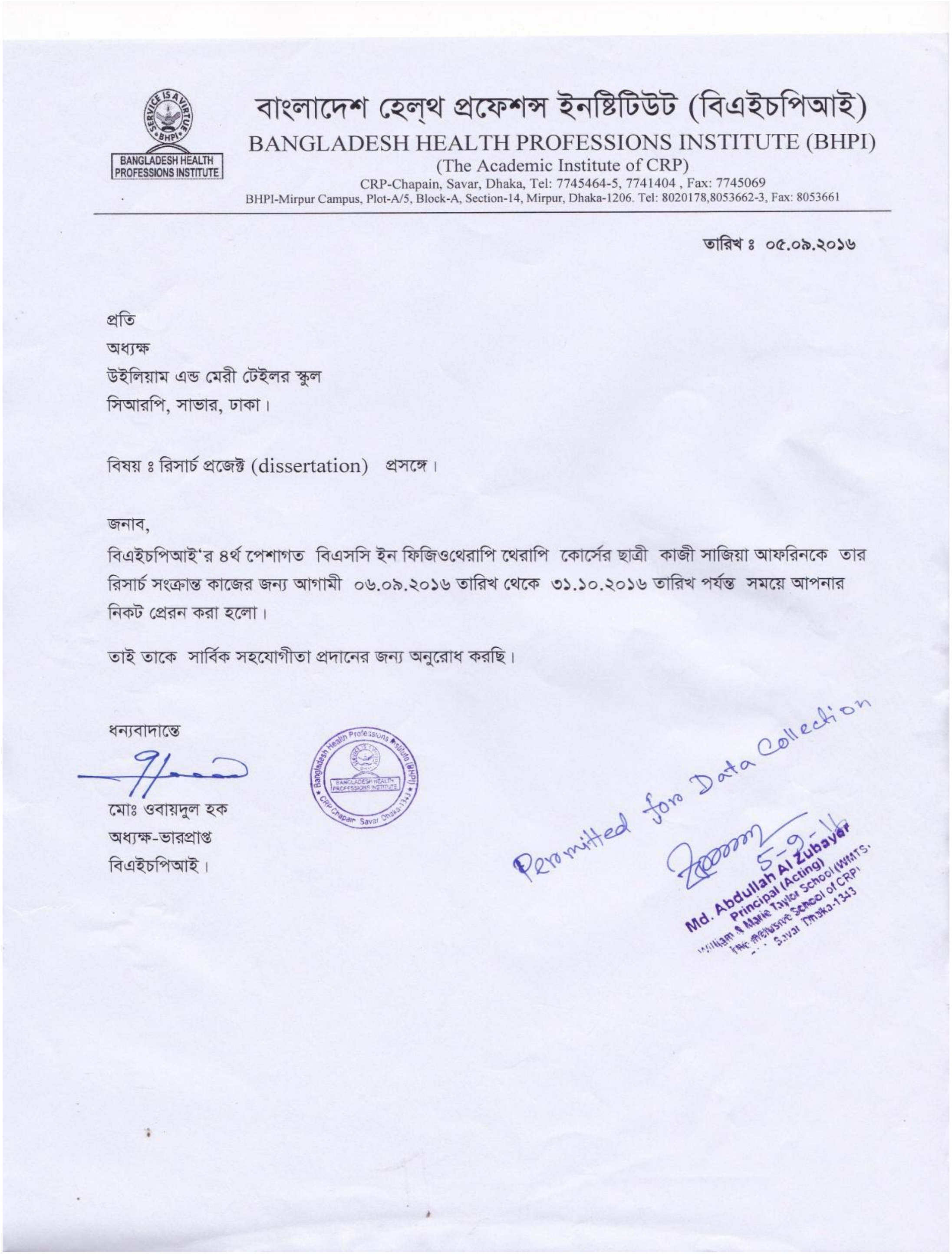
HOSNEARA PERVEEN
Incharge, Paediatric Unit
CRP Savar, Dhaka.

Forwarded
04/09/16

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

Approved
25/09/16

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



বাংলাদেশ হেল্‌থ প্রফেশন্স ইনষ্টিটিউট (বিএইচপিআই)
BANGLADESH HEALTH PROFESSIONS INSTITUTE (BHPI)
(The Academic Institute of CRP)
CRP-Chapain, Savar, Dhaka, Tel: 7745464-5, 7741404 , Fax: 7745069
BHPI-Mirpur Campus, Plot-A/5, Block-A, Section-14, Mirpur, Dhaka-1206. Tel: 8020178,8053662-3, Fax: 8053661

তারিখ ঃ ০৫.০৯.২০১৬

প্রতি
অধ্যক্ষ
উইলিয়াম এন্ড মেরী টেইলর স্কুল
সিআরপি, সাভার, ঢাকা।

বিষয় ঃ রিসার্চ প্রজেক্ট (dissertation) প্রসঙ্গে।

জনাব,

বিএইচপিআই'র ৪র্থ পেশাগত বিএসসি ইন ফিজিওথেরাপি থেরাপি কোর্সের ছাত্রী কাজী সাজিয়া আফরিনকে তার রিসার্চ সংক্রান্ত কাজের জন্য আগামী ০৬.০৯.২০১৬ তারিখ থেকে ৩১.১০.২০১৬ তারিখ পর্যন্ত সময়ে আপনার নিকট প্রেরন করা হলো।

তাই তাকে সার্বিক সহযোগীতা প্রদানের জন্য অনুরোধ করছি।

ধন্যবাদান্তে

মোঃ ওবায়দুল হক
অধ্যক্ষ-ভারপ্রাপ্ত
বিএইচপিআই।

Permitted for Data Collection
5-9-16

Md. Abdullah Al Zubayer
Principal (Acting)
William & Marie Taylor School (WMTS,
The Inclusive School of CRP)
Savar Dhaka-1343

Consent Form

Assalamualaikum,

I am Kazi Sazia Afrin, 4th Professional, B.Sc. in Physiotherapy student, Bangladesh Health Professions Institute (BHPI) under the Faculty of Medicine, University of Dhaka. To obtain my Bachelor degree, I have to conduct a research project and it is a part of my study. My research title is **"Health related quality of life of children with cerebral palsy among 3-12 years old**" To fulfill my research project, I need to some information from you to collect data. So, you can be a respected participant of this research and the conversation time will be 20-30 minutes. I would like to inform you that this is a purely academic study and will not to be used for any other purposes. I assure that all data will be kept confidential. Your participation will be voluntary. You may have the rights to withdraw consent and discontinue participation at any time of the study. You also have the right to reject a particular question that you don't like.

If you have any query about the study, you may contact with my supervisor Ehsanur Rahman, Assistant professor, dept. of Physiotherapy, BHPI, CPR, Savar, and Dhaka-1343.

Do you have any questions before start this session?

So, can i proceed with the interview?

Yes No

Signature of the mother/caregiver and Date …………………………….

Signature of the witness and Date …………………………………

Signature of the researcher and Date ……………………………..

সম্মতি পত্র

আসসালামুআলাইকুম,

আমি কাজী সাজিয়া আফরিন, ৪র্থ পেশাগত, বাংলাদেশ হেলথ প্রফেশনস ইন্সটিটিউট (বিএইচপিআই), ঢাকা বিশ্ববিদ্যালয়ের মেডিসিন অনুষদের একজন ছাত্রী। আমার ব্যাচেলর ডিগ্রী প্রাপ্তির জন্য আমার একটি গবেষণা পরিকল্পনা পরিচালনা কর তে হবে এবং এটা আমার পড়াশোনার একটি অংশ। আমার গবেষণা প্রকল্পটি হচ্ছে **“সেরিব্রালপালসি শিশুদের স্বাস্থ্য সম্পর্কিত জীবন মান ৩-১২ বছরের মধ্যে”.**আমার গবেষণা প্রকল্পটি পূরণে আমার কিছু তথ্য সংগ্রহ করা প্রয়োজন । সুতরাং এই গবেষণার জন্য অংশগ্রহণকারীর সম্মতি প্রয়োজন এবং তথ্য সংগ্রহের জন্য গবেষক অংশগ্রহনকারীর কাছ থেকে ২০-৩০ মিনিট সময় নিবেন। আমি আপনাকে অবহিত করছি যে, এটি একটি একাডেমিক গবেষণা এবং অন্য কোন উদ্দেশ্য ব্যাবহার করা হবে না । আমি আশ্বস্ত করতে চাই যে,সব তথ্য গোপন রাখা হবে। অংশগ্রহণকারী যে কোন মুহূর্তে সম্মতি প্রত্যাহার করতে পারেন। এ ছাড়াও আপনি যে প্রশ্নটি পছন্দ করেন না সেট্রি উত্তর না দেওয়ার অধিকার আছে।

শুরু করার আগে আপনার কি কোন প্রশ্ন আছে?

সুতরাং, আমরা কি ইন্টারভিউর দিকে এগিয়ে যেতে পারি? ☐ হ্যাঁ ☐ না

অংশগ্রহণকারীর(মা/রক্ষনাবেক্ষক) স্বাক্ষরওতারিখ......... ঠিকানা.........................

মোবাইল নং....................... সাক্ষীর স্বাক্ষর ও তারিখ...........

তথ্য সংগ্রহকারীর স্বাক্ষর ও তারিখ............. গবেষকের স্বাক্ষর ও তারিখ.................

Questionnaire English

Title-Health related quality of life of children with cerebral palsy among 3-12 years old.

Respondent Name: Date of the interview:

Mobile no: Patient ID: Children's Age: Father's Age:

Mother's Age: Child diagnosed by:

Part-1: Socio Demographic Information

Question Number	Questions/ Information on	Coding Category
1.1	Sex	Male=1 Female=2
1.2	Mother's Educational level	Illiterate=1,Literate=2,Primary=3,SSC=4,HSC=5, Graduation=6, Masters and Above=7
1.3	Have you got cousin marriage?	Yes=1, No=2
1.4	What was your age during birth of this child?	18-22 year=1; 22-26 year=2; 26-30 year=3; 30-35 year=4
1.5	What was your area of living?	Urban=1; Rural=2
1.6	After birth child have the child was get any diseases?	Jaundice=1,Pneumonia=2 Epilepsy=3,Dehydration=4 Seizure=5,Not at all=6
1.7	After birth child have any	Birth injury=1,Birth asphyxia=2

Part-2: Health related quality of life of children with cerebral palsy

Life Assessment Questionnaire-English

1. Within the last year how many times have you been consulting a doctor about your child except school doctor or family? (Please circle one of the points given below)

a. 0 b.1 c. 2-5 d. 6-12 e.13+

2. Within the last year has your child stayed at hospital for any duration? (Please point out the total amount of duration that you have spent in form of week)

a. 0 b. below 1 c. 1-3 d. 4-26 e. 27+

3. Within the last year how many operations have been done of your child? (Please circle one of the points given below)

a. 0 b. 1 c. 3 d. 4+

4. Within the last year was there any plaster in your child's leg, hand or any part of the body? (Please point out the total amount of duration that you have spent in form of week)

a. 0 b. below 6 c. 7-11 d. 12-17 e.18+

5. Within the last year has your child had to put on (bear) some form of support for leg or any other part of body? (Please point out the total amount of duration that you have spent in form of week)

a. 0 b. 1 c. 2 d. 3 e.4 +

6. Last day how many tablets, pills & doses medicine did your child takes? (Please circle one of the points given below)

a.0 b. 1-4 c. 5-8 d.9 -12 e. 13 +

7. Recently did your child take any special food for any reason? (Please circle one of the points given below)

a. Yes b. No

8. Within the last year how many times have your child fainted or lost memory? (Please circle one of the points given below)

a. Have not fainted for a single time

b. Fainted for a single time per month.

c. Fainted for night on day in most of the week .

d. Often frequently fainted with the specific time.

9. Within the last year have you been consulting any expert about your child for his /her behavioral problem? (Please circle one of the points given below)

a. Yes b. No

10. Within the last Year how many times have you been consulting any therapist about your child? (Please circle one of the points given below)

a. 0 b. 1 c. 2-12 d.13 -52 e.53+

11. Recently which facility ration money has taken your child that given below?

(Please circle one of the points given below)

a. Facility from health visitor

b. Facility from family help

c. Facility from Social worker

d. Facility from society nurse

e. Charitable facility

f. living ration for unable .

g. Continuous ration.

12. How many kinds of particular tools have your child at home which is necessary for now or any time? (Please circle one of the points given below)

a. 0 b. 1-3 c.4-7 d.8-10 e.11+

13. Within the last year how much money has spent by your family for your child to buy these particular tools or take care? (Please circle one of the points given below)

a. 102.43- 10243 b. 10345.43- 20186

c. 20588.43 - 30729 d. 30431.43+

14. Within the last year without buying this particular tools how much excess money has your family spent which is not filled by donation ration money? (Please circle one of the points given below)

a. 102.43- 10243 b. 10345.43 - 20186 c. 20588.43- 30729 d.30431.43+

15. Within the last year was there any modification has done at your child's present home?(Please circle one of the points given below)

a. Yes b. No

16. Please point out how many modifications have arranged or thought as necessary? (Please circle one of the points given below)

a. 0 b. 1-3 c. 4-7 d. 8-10 e.11+

17. Please tick in one place for every work mentioned below which point out generally how much you help your child to do that work, for every work mentioned below:

	No help given	some help care given	has to be donefor him
Cleaning hand	-	-	-
Eating a bowl of food	-	-	-
Putting on a vest/T-shirt	-	-	-
Doing up buttons or buckles	-	-	-
Getting out of bed	-	-	-
Getting out of bath	-	-	-
Going to the toilet	-	-	-

Going upstairs	-	-	-
Getting in and out from car	-	-	-
Opening doors	-	-	-
Taking up an object from the floor	-	-	-
Carrying a drink the distance of a room	-	-	-

18. Last time while you spent a full day with your child how many times did you need to lift him?

19. Last week during night how many times did your child need help?(Please circle one of the points given below)

a. 0 b. 1-3 c. 4-7 d. 8-10 e. 11+

20. Please make a list in which area your child needed help in a normal day.

21. (a) how many rooms are in your child home (without halls & balcony)?

(b) Last week how many times your child entered into this?

(c) How many of these your child entered into without help?

22. Does your child need any help to enter or leave from home?(Please circle one of the points given below)

a. Yes b. No

23. Last week how many distance your child went out without help? (Please circle one of the points given below)

a. 0 b.1-100 yard c. 101 -440 yard d. ¼ -1/2 mole e.1/2 + miles

24. Last week how many times your child went out by himself/herself? (Please circle one of the points given below)

a.0b.1-7 c.8-13 d.14-20 e.21+

25. Last week without nursery/school how many times your child have done long journey by any types of vehicle? (Please circle one of the points given below)

a. 0 b.1-3 c.4-7 d.8-10 e.11+

26. At present which type of nursery/school your child is giving attention?

-None

-Pre-school (e.g. nursery, play group etc.)

-Special-preschool

-Infant/primary without special support

-Infant/primary with special support

-Special school: physical disability
-Special school: Learning difficulties

-Home teaching (including carry charge)

-Others (please specify)…….

27. How many days your child attend school? (Please circle one of the points given below)

a. Part-time b. Daily c. Weekly d. Boarding e. Full time boarding

28. How much time takes your child to travel from home to school? (Please circle one of the points given below)

a. 0-15 minutes b.16-30 minute c.31-45 minutes d.46 minutes-1hour e.1 hour+

29. Last week without school time how many friends your child has met? (Please circle one of the points given below)

a. 0 b.1-3 c.4-7 d.8-10 e.11+

30. Do you have any local friends or family who can help you whenever you need? (Please circle one of the points given below)

a. Yes b. No

31. Do you think your local people are generally helpful and know about your child? (Please circle one of the points given below)

a. Yes b. No c. Sometimes

32. Do you think your child somehow interrupt your social life? (Please circle one of the points given below)

a. Yes b. No c. Sometimes

33. Do you feel any problems because of your child while spending family vacation? (Please circle one of the points given below)

a. Yes b. No

34. Your child stays with whom? (Please tick over the one that are given below)

○ Stay with birth parents
○ Stay with one birth parent
○ Stay with neither birth parents (grandparents, foster parents, adoptive parents)

35. Please describe, did any of your family member need to change job to make easy to look after your child? (Please circle one of the points given below)

36. As a parent/care giver do you think your child create extra pressure? (Please circle one of the points given below)

a. Never b. Slight c. Severe

37. Do you think your child create any extra pressure over other member of your family? (Please circle one of the points given below)

a. No other children b. None c. Slight d. Severe

Thank you for your time and answering these questions. If you have any opinion please you can tell.

প্রশ্নাবলী-বাংলা

শিরোনামঃ“সেরিব্রাল পালসি শিশুদের স্বাস্থ্য সম্পর্কিত জীবন মান ৩-১২ বছরের মধ্যে”.

শিশুর নামঃ সাক্ষাতের তারিখঃ

আইডিঃ শিশুর বয়সঃ

শিশুর বাবার বয়সঃ শিশুর মায়ের বয়সঃ

রোগসনাক্তকারি, শিশুডাক্তারঃ

পর্ব-১ : সামাজিক-বৈষয়িক তথ্যাবলী

প্রশ্ন নং	প্রশ্ন	উত্তর এবং কোড
১.১	লিঙ্গঃ	ছেলে=১ মেয়ে=২
১.২	মায়ের শিক্ষাগত যোগ্যতা-	নিরক্ষর=১, স্বাক্ষরজ্ঞান=২, প্রাইমারি=৩, এসএসসি=৪, এইচএসসি=৫, ডিগ্রী=৬, মাস্টার্স=৭
১.৩	আপনার কি আত্মীয়ের মধ্যে বিয়ে হয়েছে?	হ্যাঁ=১ না=২
১.৪	আপনার বয়স কত ছিল এই বাচ্চা জন্মের সময়?	১৮-২২ বছর=১; ২৩-২৬বছর =২; ২৭ – ৩০বছর = ৩ ; ৩১ -৩৫বছর=৪

১.৫	আপনি কোথায় বাস করেন ?	গ্রাম = ১ শহরে = ২
১.৬	জন্মের পর কি শিশু কোন রোগে আক্রান্ত হয়েছিল?	জন্ডিস=১ নিউমনিয়া=২ খিচুনী=৩ পানি শুন্যতা=৪ কোনটি না=৫
১.৭	জন্মের সময় কি আপনার শিশুর কিছু ছিল?	জন্মগত আঘাত=১ জন্মের পর অক্সিজেন এর ঘাটতি=২

LAQ-প্রশ্নাবলী

১। গত বছরের মধ্যে কতবার আপনার সন্তানকে বিদ্যালয়ের ডাক্তার অথবা পারিবারিক ডাক্তার ছাড়া অন্য কোন ডাক্তার দেখিয়েছেন? (দয়া করে উল্লেখিত একটিতে গোল করুন)

ক. ০ খ . ১ গ. ২-৫ ঘ . ৬-১২ ঙ . ১৩+

২। গত বছরের মধ্যে কি আপনার সন্তান কেযে কোন সময়ের জন্য হাসপাতালে থাকতে হয়েছিল?অনুগ্রহপূর্বক হাসপাতালে ব্যবহৃত সময়ের একটি সামগ্রিক হিসাব সপ্তাহের হিসাব আকারে নির্দেশ করুন। (দয়া করে উল্লেখিত একটিতে গোল করুন)

ক. ০ খ. ১ এর কম গ. ১-৩ ঘ. ৪-২৬ ঙ. ২৭+

৩।গত বছরের মধ্যে কতবার আপনার সন্তানের অপারেশান সম্পন্ন হয়েছিল? (দয়া করে উল্লেখিত একটিতে গোল করুন)

ক. ০ খ. ১ গ. ২ ঘ. ৩ ঙ. ৪+

৪। গত বছরের মধ্যে আপনার সন্তানের পা, হাত অথবা তার শরীরের কোন অংশেকি প্লাস্টার ছিল? অনুগ্রহপূর্বকপ্লাস্টারকৃতঅবস্থায় আপনার শিশুকে ঠিক কতদিন ব্যয় করতে হয়েছিল তার একটি সামগ্রিক হিসাব সপ্তাহের হিসাব আকারে নির্দেশ করুন। (দয়া করে উল্লেখিত একটিতে গোল করুন)

ক. ০ খ. ৬এর কম গ. ৭-১১ ঘ. ১২-১৭ ঙ. ১৮ +

৫। গত বছরের মধ্যে আপনার সন্তানকে কি শরীর অথবা পা সহায়ক কিছু পরিধারন করতে হয়েছিল? অনুগ্রহপূর্বক পরিধানকৃত সময়ের সামগ্রিক হিসাব সপ্তাহের হিসাব আকারে নির্দেশ করুন। (দয়া করে উল্লেখিত একটিতে গোল করুন)

ক. ০ খ. ১-১৬ গ. ১৭-৩২ ঘ. ৩৩-৫১ ঙ. ৫২+

৬। গতকাল আপনার সন্তান কতগুলো ট্যাবলেট, বড়ী, অথবা ঔষধের মাত্রা নিয়েছিল? (দয়া করে উল্লেখিত একটিতে গোল করুন)

ক. ০ খ. ১-৪ গ. ৫-৮ ঘ. ৯-১২ ঙ. ১৩+

৭। আপনার সন্তান কি বর্তমানে কোন কারনে একটি বিশেষ খাবার গ্রহন করছে? (দয়া করে উল্লেখিত একটিতে গোল করুন)

ক. হ্যাঁ খ. না

৮। আপনার সন্তানগত বছরের মধ্যে কতবার জ্ঞান হারানো অথবা স্মৃতিনাশক কোন অসুখ দ্বারা আক্রান্ত হয়েছিল? (দয়া করে উল্লেখিত একটিতে গোল করুন)

ক. একবারও জ্ঞান হারায় নি।

খ. প্রতি মাসে একবার জ্ঞান হারিয়েছিল।

গ. বেশির ভাগ সপ্তাহেই দিনে অথবা রাতে জ্ঞান হারিয়েছিল।

ঘ. প্রায়ই বারবার একটি নির্দিষ্ট সময় পরপর মূর্ছা জ্ঞান হারিয়েছিল।

৯। আপনার সন্তানকে গত বছরের মধ্যে তার আচারনগত সমস্যার কারনে কোন বিশেষজ্ঞ দ্বারা দেখিয়েছেন? (দয়া করে উল্লেখিত একটিতে গোল করুন)

ক. হ্যাঁ খ. না

১০। গত বছরের মধ্যে আপনার সন্তানকে কতবার কোনো থেরাপিস্ট দ্বারা দেখিয়েছেন? (দয়া করে উল্লেখিত একটিতে গোল করুন)

ক. ০ খ. ১ গ. ২-১২ ঘ. ১৩-৫২ ঙ. ৫৩+

১১। বর্তমানে আপনার সন্তান নিম্ন উল্লেখিত কোন সেবা / ভাতা গ্রহন করছে? (দয়া করে উল্লেখিত একটিতে গোল করুন)

ক. স্বাস্থ্ পরিদর্শক থেকে সাহায্য।

খ. পারিবারিক সাহায্য।

গ. সামাজিক কর্মী থেকে সাহায্য।

ঘ. আঞ্চলিক সেবিকা হতে সাহাযজ।

ঙ. স্বেচ্ছাকৃত সুযোগসুবিধা।

চ. অক্ষমতায় জীবনধারনের ভাতা।

ছ. চলমান ভাতা ।

১২। আপনার সন্তানের জন্য বাড়িতে কত ধরনের বিশেষ উপকরন আছে যা বর্তমানে অথবা কখনো অপরিহার্য হয়েছে? (দয়া করে উল্লেখিত একটিতে গোল করুন)

ক. ০ খ. ১-৩ গ. ৪-৭ ঘ. ৮-১০ ঙ. ১১+

১৩। গত বছরের মধ্যে আপনার সন্তানের জন্য এমন বিশেষ উপকরন ক্রয় এবং রক্ষণাবেক্ষন করতে পরিবারের আর্থিক কি খরচ হয়েছে? (দয়া করে উল্লেখিত একটিতে গোল করুন)

ক. ০

খ . ১০২.৪৩ -১০২৪৩

গ. ১০৩৪৫.৪৩ -২০১৮৬

ঘ. ২০৫৮৮.৪৩ - ৩০৭২৯

ঙ. ৩০৮৩১.৪৩ +

১৪। গত বছরে আপনার পরিবারের বিশেষ উপকরণ ক্রয় ছাড়া অতিরিক্ত কি পরিমান আর্থিক খরচ হয়েছিল যেটা অনুদান এবং ভাতা দ্বারাপুরন হয়নি। (দয়া করে উল্লেখিত একটিতে গোল করুন)

ক. ০

খ.১০২.৪৩ -১০২৪৩

গ. ১০৩৪৫.৪৩ - ২০১৮৬

ঘ. ২০৫৮৮.৪৩ - ৩০৭২৯

ঙ. ৩০৮৩১.৪৩ +

১৫। গত বছরে আপনার সন্তানের জন্য আপনার সন্তানের বর্তমান বাড়িতে কোন কিছু কি পরিবর্তন করতে হয়েছে?

ক. হ্যাঁ খ. না

যদি হ্যাঁ হয়, কতগুলো পরিবর্তন করা হয়েছে...... (দয়া করে উল্লেখিত একটিতে গোল করুন)

ক. ১-৩ খ. ৪-৭ গ. ৮-১০ ঘ. ১১+

১৬। অনুগ্রহপূর্বক নির্দেশ করুন কতগুলো পরিবর্তনের পরিকল্পনা করা হয়েছে অথবা প্রয়োজনীয় হিসেবে ধরা হয়েছে? (দয়া করে উল্লেখিত একটিতে গোল করুন)

ক.০ খ. ১-৩ গ. ৪-৭ ঘ. ৮-১০ ঙ. ১১+

১৭। নিম্ন উল্লেখিত প্রত্যেকটি কর্মকাণ্ডের জন্য দয়া করে একটি জায়গায় টিক চিহ্ন দিন যেটা নির্দেশ করে আপনার শিশুর কাজটি সম্পন্ন করতে সাধারণত আপনি কি পরিমান সাহায্য করেন -

	কোন সাহায্য দেওয়া হয় নি	কিছু সাহায্য করা হয়েছে	তার জন্য করে দেওয়া হয়েছে
হাত ধোয়া-	-	-	-
এক বাটি খাবার খাওয়া-	-	-	-
কাপড় পরিধান -	-	-	-
বোতাম অথবা ফিতালাগানো -	-	-	-
বিছানা থেকে ওঠা -	-	-	-
গোসলে বের হওয়া -	-	-	-
টয়লেটে যাওয়া -	-	-	-
সিঁড়ি বেয়ে ওঠা -	-	-	-
গাড়িতে ঢোকা এবং বের হাওয়া -	-	-	-
দরজা খোলা -	-	-	-
মেঝে থেকে একটা জিনিস নেওয়া -	-	-	-
ঘরের দুরত্বে কোন পানীয় বহন করা -	-	-	-

১৮। শেষবার একটি পুরোদিন আপনার সন্তানের সাথে থাকা অবস্থায় ,কত বার তাকে কোলে নিতে হয়েছিল?

১৯। গত সপ্তাহের মধ্যে রাতের বেলা আপনার সন্তানের কতবার সাহায্যের দরকার হয়েছিল? (দয়া করে উল্লেখিত একটিতে গোল করুন)

ক. ০ খ. ১-৩ গ. ৪-৭ ঘ. ৮-১০ ঙ. ১১+

২০। অনুগ্রহ পূর্বক তালিকা করুন যেখানে একটি সাধারণ দিনের কাজে আপনার শিশুর আর কোন জায়গায় সাহায্যের প্রয়োজন হয় ?

২১। ক)আপনার শিশুর বসবাসের জায়গায় কতোগুলো ঘর আছে? (বড় ঘর এবং বারান্দা ছাড়া)

খ)গতসপ্তাহে কতবার আপনার শিশু ওগুলোতে গিয়েছিল ?

গ)এর মধ্যে কতগুলোতে আপনার শিশু সাহায্য ছাড়া প্রবেশ করেছিল?

২২। আপনার শিশুর কি সাধারণত ঘরে ঢুকতে এবং বের হতে সাহায্যের প্রয়োজন হয়? (দয়া করে উল্লেখিত একটিতে গোল করুন)

ক. হ্যাঁ খ. না

২৩। গতসপ্তাহে আপনার সন্তান সাহায্য ছাড়া কতটুকু দুরত্বে বাহিরে গিয়েছিল? (দয়া করে উল্লেখিত একটিতে গোল করুন)

ক. ০ খ . ১-১০০ গজ গ . ১০১- ৪৪০ গজ ঘ. ১/৪ - ১/২ মাইল ঙ. ১/২ + মাইল

২৪। গত সপ্তাহে কতবার আপনার শিশু নিজে নিজে ঘ রের বাহিরে গিয়েছিল? (দয়া করে উল্লেখিত একটিতে গোল করুন)

ক. ০ খ. ১-৭ গ. ৮-১৩ ঘ. ১৪ -২০ ঙ. ২১+

২৫। শিশুশালা / বিদ্যালয় যাওয়া ব্যতীত আপনার শিশু গতসপ্তাহে কতবার দীর্ঘ সময় বাহিরে ভ্রমণ এ গিয়েছিল যেখানে কিছু ধরনের যানবাহনের প্রয়োজন হয়েছিল? (দয়া করে উল্লেখিত একটিতে গোল করুন)

ক. ০ খ. ১-৩ গ. ৪-৭ ঘ. ৮-১০ ঙ. ১১+

২৬। আপনার সন্তান বর্তমানে কোন ধরনের শিশুশালা /বিদ্যালয়ে মনোযোগ দিচ্ছে? (দয়া করে উল্লেখিত একটিতে গোল করুন)

- কোনটি না
- প্রাক বিদালয় (উদাহরণ - শিশুশালা , খেলাধুলা শ্রেণী ইত্যাদি)
- বিশেষ প্রাক বিদ্যালয়
- শিশু/প্রাথমিক বিদ্যালয়ের বিশেষ সাহায্য ব্যতিত
- শিশু/প্রাথমিক বিদ্যালয়ের বিশেষ সাহায্যে
- বিশেষ বিদ্যালয় (শারীরিক অক্ষমতা)
- ,, ,, ,, (শিক্ষা অসুবিধা)
- বাড়ির শিক্ষা (বহনমূল্য সহ)
- অন্যান্য (দয়া করে নির্দিষ্ট করুন).........

২৭। আপনার শিশু কতদিন বিদ্যালয়ে অংশগ্রহন করে? (দয়া করে উল্লেখিত একটিতে গোল করুন)

ক.খন্ডকালীন খ. প্রতিদিন গ. সাপ্তাহিক ঘ. আবাসিক ঙ.পূর্ণকালীন আবাসিক

২৮। আপনার শিশুর বাড়ি থেকে বিদ্যালয়ে যাতায়াত করতে আনুমানিক কত সময় লাগে? (দয়া করে উল্লেখিত একটিতে গোল করুন)

ক. ০-১৫ মিনিট খ. ১৬-৩০ মিনিট গ. ৩১-৪৫ মিনিট ঘ. ৪৬- ১ ঘণ্টা

ঙ. ১ ঘণ্টা+

২৯। গত সপ্তাহে বিদ্যালয়ের সময়ের বাহিরে আপনার শিশুর কত জন বন্ধুবান্ধব এর সাথে দেখা হয়েছে? (দয়া করে উল্লেখিত একটিতে গোল করুন)

ক. ০ খ. ১-৩ গ. ৪-৭ ঘ. ৮-১০ ঙ. ১১ +

৩০। আপনার কি স্থানীয় কোন পরিবার অথবা বন্ধুবান্ধব আছে যারা আপনাকে যখন প্রয়োজনহয় সাহায্য করতে পারে? (দয়া করে উল্লেখিত একটিতে গোল করুন)

ক. হ্যাঁ খ. না

৩১। আপনি কি মনে করেন আপনার সন্তানের ব্যাপারে সাধারণত আপনার এলাকার লোকজন সহযোগী এবং বোঝে ? (দয়া করে উল্লেখিত একটিতে গোল করুন)

ক. হ্যাঁ খ. না গ. মাঝেমাঝে

৩২। আপনি কি মনে করেন আপনার সন্তান কোনভাবে আপনার সামাজিক জীবনে বাঁধা দিচ্ছে? (দয়া করে উল্লেখিত একটিতে গোল করুন)

ক. হ্যাঁ খ. না গ. মাঝেমাঝে

৩৩। আপনার সন্তানের কারনে আপনার পারিবারিক ছুটি কাটাতে কি কোন সমস্যা বোধ হয়? (দয়া করে উল্লেখিত একটিতে গোল করুন)

ক. হ্যাঁ খ. না

৩৪। আপনার শিশু কার সাথে থাকে? (দয়া করে উল্লেখিত একটিতে টিক চিহ্ন দিন)

ক. জন্মদাতা পিতামাতা উভয়ের সাথে

খ. জন্মদাতা পিতা অথবা মাতার সাথে

গ. জন্মদাতা পিতামাতা কারো সাথেই না (দাদা-দাদি, পালকপিতামাতা, দত্তক পিতামাতা)

৩৫। অনুগ্রহপূর্বক বর্ণনা করুন আপনার শিশুর দেখাশোনা সহজ করার জন্য আপনার পরিবারের কোন সদস্যকে কি কর্মস্থল পরিবর্তন করতে হয়েছে?

৩৬। একজন পিতামাতা দেখাশোনাকারী হিসেবে আপনি মনে কি করেন আপনার শিশু অতিরিক্ত চাপ দিচ্ছে? (দয়া করে উল্লেখিত একটিতে গোল করুন)

ক. কখনই না খ. সামান্য গ. অনেক

৩৭। আপনি কি মনে করেন আপনার শিশু পরিবারের অন্যান্য শিশুদের উপর যে কোনো অতিরিক্ত চাপ দিচ্ছে? (দয়া করে উল্লেখিত একটিতে গোল করুন)

ক. কোন শিশুকে না খ. কখনো না গ. সামান্য ঘ. অনেক

ধন্যবাদ, এই প্রশ্নগুলোর যথাযথ উত্তর দিতে সহায়তা করার জন্য এবং মূল্যবান সময় দেওয়ার জন্য । অনুগ্রহপূর্বক এ সম্পর্কে আপনার মতামত স্বাধীনভাবে প্রকাশ করুন ।