INFLUENCE OF THE PARTICIPATION IN THE SELF- CARE ACTIVITIES ON THE QUALITY OF LIFE OF THE SCHOOL GOING CHILDREN WITH CEREBRAL PALSY

By

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This thesis is submitted in total fulfillment of the requirements for the subject RESEARCH 2 & 3 and partial fulfillment of the requirements for the degree:

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Statement of authorship

Except where reference is made in the text of the thesis, this thesis contains no material published elsewhere or extracted in whole or in part form a thesis presented by me for any other degree or diploma or seminar.

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Dedication

Dedicated to my beloved parents and honorable teachers.

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Abstract

Aim of the study: The overall aim of the study is to find out the influence of the participation in the self-care activities on the quality of life of children with cerebral palsy.

Objectives of the study: To investigate the aim of the study there have three objectives: to find out the quality of life of the children with CP; to find out the participation of the self-care activities of the children with CP and to investigate whether QOL is influenced by the participation of the self-care activities.

Methodology: Quantitative methodology was used to conduct this study. Participants for this study were the mother of the children with cerebral palsy child who are continuing their schooling. For collecting data 60 mothers were selected conveniently from these schools. Two structured standardized questionnaire with some demographic and socio-economic information was used to investigate the objectives of the study.

Result: Among the 60 children with CP, 58% were boys and 42% was girls. Physical well-being was the lowest in score (mean- 42.15) from different dimension of the QOL and family and social contact was highest in mean score which are respectively 68.02 and 62.7. Most of children like the company of parent and feel happy to stay at home. Among the 25 girls children with Cerebral Palsy 16 (64%) was scored as poor (0-5) and 9 (36%) was scored as good (5.1-10). Otherwise, among the 35 boys children with cerebral palsy 27 (77.1%) children was scored as poor (0 -5) and 8 (22.9%) children was scored as good (5.1 -10). And in case of the correlation between the participation in the self-care activities and QOL, there have a strong and significant positive correlation between the dimensions of QOL (self-esteem, social contact and school) with the participation of the self- care activities. This study has also shows the correlation between the dimension of the QOL (physical well-being, emotional well- being, long term illness) and the participation of the self- care activities which was not always in positive direction.

List of Abbreviation

BHPI-Bangladesh Health Professions Institute

CRP-Centre for the Rehabilitation of the Paralyzed

CP-Cerebral palsy

HRQOL- Health Related Quality of Life

INDCP- International Network on the Disability Creation Process

Life-H- Life Habit

QOL- Quality of Life

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List of Table:

List of Graph

Content

Title **Page Number**

Chapter-1: Introduction

Chapter-3: Methodology

Chapter-4: Result and Discussion

Chapter-5: Discussion

Chapter-6: Recommendation and Conclusion

Chapter-1: Introduction

1.1 Background

Disability is part of human state. Almost everyone will be temporarily or permanently impaired at some point in life (World Health Organization 2011). Worldwide 15.3% people are living with different kind of disability (World Health Organization 2011). In Bangladesh, there has 1.4% person with disability, which was 0.6% at 2001 census (Hasib 2012). From the different kind of disability Cerebral Palsy (CP) is the most common type with the frequency of 1.4- 2.7/ 1000 of live birth (Tabib 2009). In 2001, the United Cerebral Palsy Foundation estimated that 764,000 children and adults in the United States carried the diagnosis of cerebral palsy with different kind of disability. In addition, they estimated that 8,000 babies, infant and 1,200 to 1,500 preschool-age children are diagnosed with cerebral palsy in every year in the United States. It is the most common childhood physical disability and affects 2 to 2.5 per 1,000 born in the United State (Krigger 2006).

The incidence of Cerebral Palsy is undefined problem of Bangladesh because it is not captured in the population census or any other survey and most of the study related with CP is based on the limited geographic location (New age 2012). In 2005 one study of Bangladesh shows that, among 2,559,222 disabled children 179, 145 (7%) have cerebral palsy (Ackerman et al 2005). Where another study about 'prevalence of disability and cerebral palsy in community' which was conducted at the seven village of Narayangonj district of Bangladesh and showed the prevalence of Cerebral Palsy which was 6.1/ 1000 (Tabib 2009). Regarding sex distribution of cerebral palsy 6.8/ 1000 boys have cerebral palsy where 5.5/1000 girls have cerebral palsy (Tabib 2009).

Cerebral palsy is a neurological disorder that appears in infancy or in early childhood and permanently affect body movements and muscle coordination but it doesn't worsen over time. Though cerebral palsy affects muscle movement, it is not caused by problems in the muscles or nerves. It is caused by abnormalities in parts of the brain that control muscle movements (NINDS Cerebral Palsy Information Page 2011). So children with CP may faces difficulties in the activities of the daily living. And the reasoning behind those difficulties are specific deficit on the motor behavior which lead deficits in motor planning that can result in slow, inefficient, behaviors (Steenbergen and Gordon 2006). It is also depends on the type or severity of the impairments (Manus, Corcoran and Perry 2008). As well this impairment is cause of their reduced number of participation (Michelsena et.al 2009). And this study is aimed to find out the influence of the participation of self-care activities on the quality of life on the basis of the context of Dhaka, Bangladesh.

Consequently it is well understood that children who has cerebral palsy, faces different kind of difficulty which is depend on the severity. And severe impairment decreased the participation of the children (Manus, Corcoran and Perry 2008). The International Classification of Functioning, Disability and Health (ICF) define participation as involvement in life situations (WHO cited in Michelsena et al. 2009). Participation is the range to which a person is actively involved in activities, for example, eating, doing sports or meeting friends; it is not what a person can or wants to do (Michelsena et al. 2009).

The basic tasks performed on a daily basis in order to engage in daily routine which are known as activities of the daily livings. According to the Occupational Therapy practice frame work II (OTPF) (American Occupational Therapy Association) activities of daily living or self- care task may include feeding, dressing, taking care of own body through grooming and personal hygiene (i.e., toilet hygiene, bowel and bladder management, bathing or showering (Shepherd as cited in AOTA 2008).

But children with CP face difficulty in participating these self-care or personal care activities due to their impairment. And this is unknown that this impaired participation whether or not influences the QOL of children with CP. Where Quality of Life is defined by The World Health Organization as ‘individuals perceptions of their position in life in the context of the culture and value system in which they live, and in relation to their goals, expectations, standards and concerns.’ So the QOL is important to know how well children with CP is living with decreased participation for achieving the better quality of life (at work 2012).

1.2 Significance of the study

This study shows a snapshot about the Quality of Life, participation in the self- care activities and a correlation between the QOL and the participation of the self- care activities of the school going children with Cerebral Palsy (CP). Although different school are working for these special needs children for their schooling with the support of Physiotherapist, Occupational Therapist, Speech and Language Therapist and teacher where Occupational Therapy is a client-centered profession concerned with prompting health and wellbeing through engaging in occupation (WFOT, 2010). But there have lack of evidence about the QOL of these school going children with CP where health and wellbeing is measured. The goal of the OT is to enable these children to participate in the activities of everyday life (WFOT, 2010). But there, the level of participation is unknown in the context of Bangladesh. Additionally it is also unknown that whether or not these level of participation in the self-care activities influence on the QOL of the children with CP. By investigating this information about QOL and participation in life habit, this study may act as evidence about the QOL of school going CP children in the field of Quality of Life research.

1.3. Aim of the Study

The overall aim of the study is to find out the influence of the participation in the self-care activities on the quality of life of children with cerebral palsy.

1.4. Objectives of the Study

- To find out the Quality of Life (QOL) of the children with Cerebral Palsy (CP)
- To find out the participation in the self-care activities of the children with CP
- To investigate whether or not QOL is influenced by the participation of the self-care activities

1.5. Hypothesis of the study

- *Alternative Hypothesis:* There is a relationship between the participation in the self-care activities and dimension of the QOL.
- *Null Hypothesis:* There is no relationship between the participation in the self-care activities and dimension of the QOL.

Chapter 2: Literature Review

Disability is part of human condition. Almost everyone will be temporarily or permanently impaired at some point in life. Only the Global Burden of Disease measures childhood disability (0–14 years) which is estimated to be 95 million (5.1%) children of which 13 million (0.7%) have "severe disability" (World Health Organization 2011). Cerebral palsy is the most common childhood disability which commonly occurs due to premature child birth. Due to the paralysis to the one side of the brain children develop impairment (sensory and motor) on the opposite side of the body. As a result they face difficulty in performing their self-care activities. And this study is aimed to find out the influence the participation of the self-care activities on the Quality of life of the children with Cerebral Palsy.

Key points: Children, Special Needs Children, Cerebral Palsy, Self- Care Activities, Participation, Life-Habit scale, Quality of life, KINDL questionnaire, special needs school and Occupational Therapy.

2.1. Children

According to the Convention on the Rights of the Child (CRC), a child means every human being below the age of eighteen (18) years unless under the law applicable to the child, majority is attained earlier (Convention on the Rights of the Child 2009). It means human being who is under eighteen years of age, unless the law of his or her country believes him or her to be an adult at an earlier age.

2.2. Special needs Children:

Children with special health care needs are those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally (Newacheck et al 2012).

According to UNICEF estimation, 130 million children are born each year. In many countries, they represent more than 50% of the population. Although neonatal mortality is declining worldwide but an estimation of WHO in 2010 shows that 3.1 million babies died during their first month of life (World Health Statistics 2011). An estimation on 2001 has showed that about 12.8% of US children need special health care. Prevalence was highest among boys, school-age children, and children in lower-income families (Dyck et al. 2004: 158). There have different type of childhood disability like Cerebral Palsy, Autism Spectrum Disorder (ASD), Attention Deficit Hyperactivity Disorder (ADHD), Down syndrome, Duchene/Becker Muscular Dystrophy and they need special care for surviving. From all of these conditions Cerebral palsy (CP) is the most common motor disability during childhood (Accardo, P. J. 2008). Almost 17 million people around the world have cerebral palsy. Up to 5000 children in the United State are diagnosed as CP in each year (‘Cerebral palsy’ 2011).

2.3. Children with Cerebral Palsy:

“Cerebral palsy (CP) describes a group of disorders of the development of movement and posture, causing activity limitations that are attributed to non-progressive disturbances that occurred in the developing fetal brain. The motor disorders of CP are often accompanied by disturbances of sensation, cognition, communication, perception, and/or behavior, and/or by a seizure disorder.”(Bax et al. 2005). CP is a disorder of abnormal control of movement and posture, appearing early in life secondary to a CNS lesion or dysfunction that is not a result of a progressive or degenerative brain disease. In other words, CP is caused by a static brain dysfunction (also called static encephalopathy). It is believed that CP is due to a defect in a developing brain, a lesion that may have had its onset in prenatal, perinatal, or postnatal period (Romantseva, L. 2006). Children can experience CP from brain injury that occurs before the cerebral development is completed. The continuous development of brain occurs until the first two years of life (Krigger 2006). After having CP the condition remains non- progressive and non- communicable (Romasis Health Care 2011).

The incidence is strongly associated with the gestational age. Prematurity is the commonest risk factor for developing CP (Mohammed M. S. J. (2006). Current evidence suggests that 70-80% of CP cases are due to prenatal factors, and that birth asphyxia accounts for <10% of Cerebral Palsy (Romantseva, L. 2006).

2.4. Cause of Cerebral Palsy

Thus, causes of CP may be various. Here are some common etiologies manifesting as CP:

- *Prenatal*

1. Hereditary-Genetically transmitted and may involve racial or familial predilections and often sex-linked. Examples: Hereditary athetosis, familial tremor, familial spastic paraplegia.

2. Acquired in utero

Prenatal infection (toxoplasmosis) rubella, or other maternal infection, aternal anemia, hypotension, e.g., following spinal anesthesia, placental infarcts, prenatal cerebral hemorrhage, direct trauma, Rh factor (controversial), diabetes, maternal malnutrition.

- *Natal*

Narcotism (due to drugs), maternal hypotension, breech deliveries with delay of the after-coming head, bleeding in the first trimester.

- *Postnatal*

Trauma-Subdural hematoma, skull fractures, wounds and contusions of the brain(accidental), infections-(more common in children than adults) meningitis, encephalitis, brain abscess, toxic causes-lead, arsenic etc., vascular accidents (more common in adults than children) congenital aneurysms, circle of Willis, hypertensive encephalopathy, emboli due to bacterial endocarditis or fat embolism, cerebrovascular thrombosis, in debilitated infants, sudden pressure changes, Anoxia-Carbon monoxide poisoning, strangulation, high altitudes, and deep pressure anoxia, hypoglycemia, neoplastic, or late development defects- Brain tumors, brain cysts, hydrocephalus (Minear 2013).

Table 1: Classification of Cerebral Palsy based on Motor Function

Type		**Involvement of the Brain**	**Symptom and Complication**
Spastic (approximately 70-80%)	✓ Quadriplegia (all 4 limbs are involve) ✓ Tetraplegia Diplegia (All 4 limbs are involves and both leg are more severely affected then arms) ✓ Triplegia (Involves 3 extremities, usually both arms and a leg.) • Hemiplegia (One side if the body is affected and the arm is more affected then the leg.) • Monoplegia (Only one limb is affected, usually an arm.)	Damage to the motor cortex	• Increased muscle tone • Increased reflexes with tendency to clonus, tendency for contractures; Flexion contractures at elbow. • Difficulty with pronating or supinating forearms; difficulty with long sitting because of hamstring contractures. • Difficulty changing diapers because of decreased range in abduction of hips; scissoring in lower extremities. • Toe walking gait.

Athetoid **(Approximately 10-20% of all)**	Damage to the basal ganglia of the midbrain.	• Involuntary movements of hand, feet, arms, muscles of the face or tongue. • Movements are usually twisting in nature, aggravated by stress, disappear in sleep.
Ataxic **(Approximately 5-10% of all)**	Damage to the cerebellum	• Poor coordination • Unsteady gait, • Difficulty with rapid or precise movements. • Impaired sense of balance and depth perception.
Mixed		• The 4th type is mixed CP the most common form includes spasticity and dystonic/ athetoid movements

(Romantseva 2006¸Minear 2013, Fox 2009, Cerebral Palsy Association 2009)

2.5. Self-Care activities:

At least 60% of the children with spastic CP had difficulties with mobility, recreation and housing, and 44% had difficulty with personal care and employment (Slot 2010). The basic tasks performed on a daily basis in order to engage in daily routine which are known as activities of the daily livings. This activity is done for the personal care.

According to the Occupational Therapy practice frame work II (OTPF) (American Occupational Therapy Association) activities of daily living or self-care task may include feeding, dressing, taking care of own body through grooming and personal hygiene (i.e., toilet hygiene, bowel and bladder management, bathing or showering (Shepherd as cited in AOTA 2008).

Most of the children go for school at the age of the 5 or 6 years old and in this age level they are expected to perform all the basic self-care activities like toileting, grooming, personal hygiene, feeding and dressing task needed for the school (Rodger and Brown 2006).

When a child has Cerebral Palsy (CP) it becomes difficult to perform all of these activities. And pattern of performing activities may change. Most of the time they are not independent in performing self-care activities. Task may be completed with adaptive devices. They performed partially. Some children with severe impairment needed a long time dependency on the carer in case of performing self-care activities (Shepherd 2005).

Table 2: Typical Age of accomplishment for sample self- feeding, toileting, Dressing, and personal hygiene and grooming Skills.

Age in Years	Self- Feeding Skills	Toileting Skills	Dressing Skills	Personal Hygiene and Grooming Skills
5	Feed self independently	-Use toilet independently (tearing toilet paper, flashing, washing hand and managing clothing) - Nighttime bowel bladder control	**General** Dresses unsupervised LE dressing Lace shoes	Comb and brushes hair with supervision Blows nose when reminded

		- anticipate toileting needs May need reminder for wiping and hand washing	Ties and unties knots	Uses brush to clean fingernail with prompting
6	Self-feeding skills become more automatic and coordinated	Has independent toileting skills	General: Choose appropriate clothes for occasion and weather Fasteners Close back zipper Ties shoes Buttons back buttons Snaps back snaps Independently choose clothing	Brushes teeth independently Rinses teeth independently Uses dental floss independently Brushes hair with minimal assistance
7-8			Independently choose clothing	Control water and temperature independently Independently wash hair
9 and older	Advanced Skills			

(Shepherd 2005)

2.6. Participation in self- care activities and Life- Habit Scale:

Due to the intrinsic impairment of the cerebral palsy children they become delayed developmentally from the developmental milestone. And they face difficulties in the participation of the self-care activities. Where the participation is defined by The International Classification of Functioning, Disability and Health (ICF) as ‘involvement in life situations’. Participation is the extent to which a person is actively involved in, for example, getting about, doing sports or meeting friends; it is not what a person can or wants to do (Michelsena 2009). The participation of the children with the special needs is Important because it helps to develop skills and competencies from friendship, express creativity, achieving physical and mental health and find the meaning and purpose of the life (Dijkers et al. 2000; Lyons 1993).

In this study participation on the self-care activities has measured by the Life- Habit scale. Life habits” which can also be called “life situations” seems to be the most adequate term to designate the regular and social activities of a person in the context of his/her actual life. Where this scale is formed for measuring the regular activities such as eating meal, communicating with other, moving around and social rules such as going to school, engaging in the social relationship, participating in the recreational activities that allow young people to survive and achieve their potentiality to survive their live. The purpose of the questionnaire is to determine the way in which the young person accomplishes the life habit (Fougeyrollas 2003).

In this scale there have 12 different domain under the activities of daily living and social roles .And in this study personal care domain has used. Because this study is aimed to find out the participation of the self-care/ personal care activities of the children with cerebral palsy. There have eight (8) different parts under the two (2) different questions. Question 1: A. level of accomplishment, B. type of assistance. And question 2: level of satisfaction. These eight different parts of self-care domain are: attending to personal hygiene, using the toilet at home and outside of the home, dressing and undressing the upper and lower half of body, putting on, removing and maintaining assistive devices, taking part in personal health care, using services provided by a medical clinic, hospital, rehabilitation center, or community clinic.

2.7 Quality of Life (QOL) and KINDL Questionnaire

The Constitution of the World Health Organization (WHO) defines health as "A state of complete physical, mental, and social well-being not merely the absence of disease (WHO 2000). Children with cerebral palsy have impaired health status. And this study will find out the quality of life of these children to find out the influence of the participation of the activities of daily living on the quality of life.

WHO defines Quality of Life as individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to significant features of their environment (WHO 2000).

Three major life domains are identified: Being, Belonging, and Becoming. The Being domain includes the basic aspects of "who one is" and has three sub-domains. Physical being includes aspects of physical health, personal hygiene, nutrition, exercise, grooming, clothing, and physical appearance. Psychological being includes the person's psychological health and adjustment, cognitions, feelings, and evaluations concerning the self, and self-control. Spiritual being reflects personal values, personal standards of conduct, and spiritual beliefs which may or may not be associated with organized religions.

Belonging includes the person's fit with his/her environments and also has three sub-domains. Physical Belonging is defined as the connections the person has with his/her physical environments such as home, workplace, neighborhood, school and community. Social Belonging includes links with social environments and includes the sense of acceptance by intimate others, family, friends, co-workers, and neighborhood and community. Community belonging represents access to resources normally available to community members, such as adequate income, health and social services, employment, educational and recreational programs, and community activities.

Becoming refers to the purposeful activities carried out to achieve personal goals, hopes, and wishes. Practical Becoming describes day-to-day actions such as domestic activities, paid work, school or volunteer activities, and seeing to health or social needs. Leisure Becoming includes activities that promote relaxation and stress reduction. These include card games, neighborhood walks, and family visits, or longer duration activities such as vacations or holidays. Growth Becoming activities promote the improvement or maintenance of knowledge and skills (Quality of Life Research Unit 2004).

In this study report are based on the objective measurement that mean parent has reported their child quality of life (Sieberer et al. 2000) and QOL is measured by using the KINDL questionnaire. The KINDL questionnaire consists of 24 Likert-scale items associated with six dimensions: physical well-being, emotional well-being, self-esteem, family, social contact, school and disease module. The sub-scales of these six dimensions with additional disease modules combined to produce a total score.

2.8 Special Needs Schools and Occupational Therapy

A large number of students with CP receive services through the school system such as physical, occupational, and speech therapy. These professionals can be valuable resources to teachers when it comes to learning strategies for working with students diagnosed with CP. The physical therapist is knowledgeable about gross motor skills as well as endurance and mobility, speech and language therapist can assist with the student's ability to communicate functionally in the school setting, while the occupational therapist can provide information about fine motor, organizational, perceptual, and self-help skills which helps the children to perform his or her activities of daily living. Occupational Therapist also suggest and support the regular education of the teachers to ensure that the classroom is organized in a manner that does not create any significant physical obstacles for the child. Because some children with CP either use a wheelchair or require walking devices, teachers should set up the classroom so that plenty of space is available for the student to move around the room and to sit comfortably at a desk. Items that may interfere with the safety of a CP child should be placed out of reach (Zachry 2011).

According to World Federation of Occupational Therapists (WFOT, 2010), “Occupational therapy is a client-centered profession concerned with prompting health and well-being through occupation. The primary goal of Occupational Therapy is to enable people to participate in the activities of everyday life. Occupational therapists achieve this outcome by working with people and communities to enhance their ability to engage in the occupations they want to, need to, or are expected to do, or by modifying the occupation or the environment to better support their occupational engagement.”

There have many schools in Bangladesh which are working for children with cerebral palsy for improving the quality of life. These schools are such as Bangladesh Prothibondhi Foundation, William and Marie Taylor School, Beautiful Mind, Dreams Angel, Alokito Shishu etc. and in this study data are collected from these schools.

School has identified as a positive and appropriate setting in which to reach children and adolescents for their opinions, attitudes, behaviors, knowledge and feelings about their perception of health. The WHO identified that ‘a health-promoting school can be characterized as a school constantly strengthening its capacity as a healthy setting for living, learning and working’ (Gray et al, 1997). In Ireland, the National Health Promotion Strategy for the years 2000-2005 identified the school as an important setting for health promotion activities (Department of Health and Children, 2000).

Schools are settings where the health of children and adolescents can be identified and where specific health issues can be addressed (St. Leger, 2004). In terms of research, the structure of the educational system provides a ready-made sampling frame in terms of age, sex, educational level, geographical area and so on(Keenaghan 2008).

2.9. Demographic information of the respondent

✓ Area of residence:

The respondents are came from different area of residence like rural, semi-rural and urban area. And which are defined as:

- *Rural* is known as a geographic area that is located outside the cities and towns and needed (Rutledge et al. 1993)
- *Urban* is **c**ity Surrounding and densely settled population. Their definition does not follow city or county boundaries and so it is difficult sometimes to determine whether a particular area is considered urban or rural (Rutledge et al. 1993).
- *Semi-rural* town, or small city (Rutledge et al. 1993).

✓ Level of education of parents

There have different educational level of the respondent which are leveled as: illiteracy, signature only, primary education, secondary education, higher education, graduate, postgraduate etc.

- *Illiteracy:* UNESCO defines the illiteracy as the condition of a person who can neither read nor write, dividing the world into literates and illiterates simplifies the nature of literacy. Today, the UNESCO definition has become more complex and relies largely on individual's ability to interpret the environment and contribute to the society in which they live. Statistically, it tends to detect the set of skills for literacy that can be applied in functional activities typical of everyday life, for example: read the bus timetable, dialing a cell phone number or reading a computer email.

- *Signature only:* person who can only write his/ her own name.

- *Primary education* (formal) refers to education, as determined by the Government, in grades 1 to 5 having prescribed national curriculum, textbook and school hours (Education for all 2000).
- *Secondary and higher education:* The pattern of education in Bangladesh consists of five years of elementary education, three years of lower or junior secondary, two years of secondary, and two years of higher secondary education (World Educational Profile 2004).
- *Graduate:* In this study graduate refers to person who has received a degree on completing a course of study, as in a university, college or school.
- *Postgraduate:* A student who has already got one degree and is studying at a university for a more advanced qualification.

Chapter-3: Methodology

The aim of the study was: finding out the influence of the participation in the self-care activities on the quality of life of children with Cerebral Palsy. And this is the framework of the method is designed to meet the aim and objectives of the study:

3.1. Study Setting

This study was conducted in six (6) different special need schools setting named: Kalyani Inclusive primary school (an academic institution of Bangladesh Prothibondhi Foundation), William and Marie Taylor Inclusive School, Beautiful Mind, Dream Angels, Alokito Shishu and Tauri Foundation etc. All of these schools are located in the Dhaka which is the capital city of Bangladesh, situated at the southern Asia, bordering the Bay of Bengal, between the India and Myanmar (Bissinger 2010).

3.2. Study Location

The study was conducted at 6 different special need schools settings which are: Kalyani Inclusive primary school is located at the Mirpur-2 Dhaka, William and Marie Taylor School in the Savar, Beautiful Mind in the Uttara, Dream Angels in the Mirpur 11, School for Gifted Children (Tauri Foundation),Alokito Shishu at the Shekhertek, Mohammadpur etc.

3.3. Study Design

This study was took a snapshot about the participation of the self-care activities and the quality of life of the children with CP for a specific time period to investigate the association between the participation in the self-care activities and the QOL of the children with CP. So cross sectional design has chosen as a design of the quantitative research method (Levin 2006).

3.4. Study Population

A survey has conducted among the parent of 115 children with CP from the special needs school and inclusive school.

Table 3: Study Population

List of Special Needs Schools	**Number of the children with CP in each school**	**List of the inclusive school**	**Number of the children with CP in each school**
1. School for Gifted Children (Tauri Foundation)	9	5. William and Marie Taylor School	39
2. Beautiful Mind	8	6. Kalyani Inclusive primary school	49
3. Dreams Angel	8		
4. Alokito Shishu	2		
Total population= 115			

3.5. Study Sample

3.5.1 *Sampling Procedure*

- ✓ In this study 'comprehensive sampling' procedure has used to select the sample from the entire group of population. From the entire population of the study who has filled up the inclusion criteria those are included as sample in the study. According to Bailey (1997), comprehensive sampling is 'A situation in which all the cases can be examined.'

3.6. Sample Selection Criteria

- ✓ *Inclusion criteria*
- Parent of those Children who is diagnosed as cerebral palsy
- Parent of the school going children aged 8 to 12 years old.
- Parent of those children who are admitted in above mentioned school
- ✓ *Exclusion criteria*

- Parent of the children who takes any recent medication changes that could affect condition from.

3.7. Sample Size

- From the population (115) of the study, parent of 60 children with CP has filled up the inclusion criteria and selected as sample for the study. So the sample size are 60.

3.8. Data Collection Instruments

3.6.1 *Questionnaire*

Two structured standardized questionnaire has used for collecting data (appendix- 4). One is for measuring Quality of Life (QOL) named KINDL questionnaire and another is for measuring the participation of the self-care activities which is presented as Life Habit (Life-H) questionnaire.

3.9. Variables

3.9.1. Independent variable

In this study independent or predictor variable is the participation of the self-care activities of the children with CP. And there have different type of variable like sex, educational qualification of the parent, participation of the self- care activities etc. which are the categorical type of independent variable. And the numerical type of independent variable is monthly income etc.

3.9.2. Dependent variable

The outcome or dependent variable is the quality of life of children with CP and the variable type is categorical.

3.10. Validity

The data was analyzed by using SPSS 16 package to reduce statistical error which is valid software. KINDL and Life Habit questionnaire was used in this study and both are standardized valid questionnaire to measure respectively the QOL and participation in the activities of daily life of the children with CP. A field test was completed to ensure the appropriateness of the language.

3.11. Reliability:

To make these questionnaires reliable the questionnaire was translated into Bengali by the following ways:

Researcher was used 2 sets of questionnaire (Quality of Life and Life Habit) with the demographic and socioeconomic information sheet. These questionnaires was in the English version. It was important to translate these questionnaires into Bengali to ensure parent comprehended and understood the questions easily. Each questionnaire was translated from English to Bengali for 2 times by the experienced translators. From these 2 different copy of Bengali questionnaire 1 was formed by taking easy and similar part of the questionnaire. This is known as forward translation. Then from the forward translation an English translation was done by the different translator who has experience on the field of translating. And finally this copy is compared with the main questionnaire. After checking and rechecking this way the formulation of final questionnaire was completed.

A field test of the questionnaire was also conducted to check the tools in the actual fields. The purpose of the field test was to gather pre-knowledge about workers response to tools. To administrate the questionnaire the researcher was trained about data collection and tools to ensure test re- test reliability.

3.12. Data collection Procedure

Investigator was contacted with the above mentioned school authorities or principle for collecting data. After getting permission of data collection principle has assigned responsible Occupational Therapist to provide information sheet, consent form and survey questionnaire to the parent of the children with CP. Two data collector has supported for collecting data with the researcher for those parent who has low educational background and faces difficulty to fill-up the questionnaire. And to fill up the questionnaire approximately 40 to 45 minutes was required.

3.13. Field Testing of the Questionnaire

Before starting data collection a field tests done among the 8 parents of both sexes. This test done at a quit place. Field-testing was important for identifying the problems of the questionnaire such as confusions about the proposed meaning of items. A problem concerning item content, including confusion about the overall meaning of items, as well as misinterpretation of individual terms or concepts was identified. Additionally using the general probing method respondents asked whether the items can be considered comprehensible and clear and whether they were difficult to answer. The outcomes of all interviews documented in the documentation.

Slight structural change was done in the life habit questionnaire as it seems complicated to understand for the respondent. In some point special notes was putted to clarify the meaning of assistive device and adaptation etc.

3.14. Ethical Consideration

First of all this study proposal was send to the authority for further suggestion, modification and so on. Then the final version of the protocol was submitted along with an application for seeking permission of data collection. Before starting data collection from each school, permission was taken from school authority by maintaining proper chain of command. And written information sheet was provided to participant to inform participant about the aim and significance of the study and if the parent client agree to participate then his or her consent was taken. But if any one disagree to participate in the study then he or she was got complete freedom to withdraw it. It was ensured that the data will only be accessed by the researcher and the supervisor of this study. Confidentiality was maintained strictly during the course of study at every step.

Chapter- 4: Data Analysis and Result

4.1. Data Analysis Process

In this study researcher has used two different scale or instrument (Kiddy-KINDL questionnaire for QOL and Life- Habit questionnaire for participation) with some demographic and socio-economic factors to investigate the objectives of study. After completing data collection data has inputted in the SPSS (Statistical Package for the Social Sciences) software, version 16.0 by following 'Introduction to SPSS (Version 16) and SPSS 16.0 Brief Guide' (University of Bristol 2010). Data has analyzed in the following way:

Step-1.Descriptive analysis of the quality of life:

In this parent reported questionnaire there have 6 subscales (24 questions) with a disease module. As the entire sample for the study has a long term illness so disease module has included as a part of the questionnaire which was recommended in the manual of KINDL questionnaire. Once the data have been entered, analysis of the items and sub-scales is carried out in following steps:

- First of all, descriptive analysis has done to investigate the frequency of the data of each domain of the QOL.
- Then recoding each domain and calculating subscale score (corresponding to the mean of the item scores), Sub-scale score transformed to a range of 0 to 100.

Step-2 Chi-squire test was completed to show the association between the gender and the level of participation of the self-care activities.

Participation of the self- care activities has measured by Life- Habit questionnaire. Where the 8 questions of personal care categories has scored by Life Habit accomplishment scale. Then calculation of accomplishment level has done by using the recommended formula And finally a total scores has done for the personal care or self- care categories.

Step-3 Investigate the correlation between the quality of life and participation in the self-care activities

Pearson correlation test was done to investigate the association between the quality of life and participation in the self-care activities. And to show the result in graph scatter plot has used.

4.2. Result of the Study

4.2.1. Profile of Respondents: Presentation of findings

The following chapters detail the findings of the objective health-related quality of life (parents understanding about the QOL of their child) of 60 children of 8 to 12 years age group from 6 special needs school. The results of their child's health and well-being across 6 dimensions of health are reported in this Chapter where basic descriptive data are presented. All data results are rounded to the nearest percentage. The valid response for each question has been used (i.e. those who did not answer the question(s) in the questionnaire are excluded in all figures and tables).

It also looks at the respondents' demographic characteristics and socio-economic background.

4.2.2. Socio-demographic characteristics

The first set of questions in the KINDL questionnaires asked the parent of the children with CP about their perceived socio-demographic characteristics (see Table 4).

From the total population (parent of 140 children with cerebral palsy) 60 parent has taken part in the study. Where 41 (68.3%) was mother and 16 (26.7%) was father within the 43.6% response rate. And 58.3% were male children and 41.7% were female children. As this study is based on different special needs school of Dhaka, Bangladesh so researcher has to note the location of the participant of the study. Where, from urban was 32 (53.3%), semi- rural 27 (45.0%) and rural 1(1.7%). Which show that a large number of participants are from the urban and semi-rural. Female Participants (mother) was from different educational level**:** illiterate: 5 (8.3%), signature only: 1 (1.7%), primary: 11 (18.3%), secondary: 14 (23.3%), higher secondary: 13 (21.7%), graduate: 12 (20.0%), post graduate 4: (6.7%) and educational level of male participants (father)of children with CP**:** illiterate: 4 (6.7%), signature only: 3 (5.0%), primary: 4 (6.7%), secondary: 11 (18.3%), higher secondary: 11 (18.3%), graduate: 12 (20.0%), post graduate 15: (25.0%). In these family father (70%) is the main income source. In some families mother (10.0%) is key person of earning where some family have record of earning of both father and mother. To show the association with different variable, socio-economic status of the respondent was collected which show that 53.3% parent are from the middle class family, 23.3%

was from the lower middle class, 16.7% from the higher middle class, 3.3% from the higher class and 3.3% from the lower class.

Table 4: Summary of socio-demographic characteristics of all respondents

	Characteristics	**Percentage**	**Number**
i.	**Sex of children with CP**		
	Boy	58.3%	35
	Girl	41.7%	25
ii.	**Questionnaire completed by**		
	Father	68.3%	41
	Mother	26.7%	16
iii.	**Area of residence of the respondent parent of children of CP**		
	Rural	1.7%	1
	Semirural	45.0%	27
	Urban	53.3%	32
iv.	**Source of income of the family**		
	Father	75.0%	45
	Mother	10.0%	6
	Both	15.0%	9
v.	**Approximate income in each month**		
	5,000 or below the 5,000	13.3%	8
	10,000:	16.7%	10
	15,000	14.0%	13
	20,000	11.7%	7
	25,000	16.7%	10
	30,000 and above 30,000	18.7%	11

vi.	**Socio-economic status of the respondent**		
	Lower class	3.3%	2
	Lower middle	23.3%	14
	Middle class	53.3%	32
	Higher middle class	16.7%	10
	Higher class	3.3%	2
vii.	**Educational level of the mother of the children with CP**		
	Illiterate:	8.3%	5
	Signature only	1.7%	1
	Primary	18.3%	11
	Secondary	23.3%	14
	Higher secondary	21.7%	13
	Graduate	20.0%	12
	Post graduate	6.7%	4
viii.	**Educational level of the father of the children with CP:**		
	Illiterate	6.7%	4
	Signature only	5.0%	3
	Primary	6.7%	4
	Secondary	18.3%	11
	Higher secondary	18.3%	11
	Graduate	20.0%	12
	Post graduate	25.0%	15

4.2.3: Describing below the result of each dimensions of KINDL questionnaire

Dimension 1: Physical well-being

Definition

This dimension discovers the physical status of the children with Cerebral Palsy in terms of their energy and fitness. The dimension looks at the child’s feeling of illness. Feelings of headache or tummy ache, being tired and worn-out are also studied. In addition, the extent to which children feels strong or full of energy is examined.

Participants were asked 4 questions relating to their physical well-being as experienced in the

last week to completing the questionnaire. Table 5shows that, from the total respondent nearly 38.4% think that their children felt ill ‘never’ or ‘seldom’, 30.0% felt ‘sometimes’ and rest of the participants (37.7%) felt ill ‘often’ or ‘all the time’. From all of the participant, 68.4% parent of children with CP stated that their child felt headache or tummy- ache ‘never’ or ‘seldom’, 23.7% parent indicate that their child felt like this ‘sometimes’ and 8.3% feel headache or tummy-ache ‘often’ or ‘all the time’. 35.0% respondent state that their children with CP was tired and worn-out for ‘never’ or ‘seldom’, 30.0% respondent state that sometime their child feel tired and worn-out. And 35.0% state that, ‘often or all the time’ their children felt tired and worn out. And 55.0% respondent state that their children with CP ‘never’ or ‘seldom’, 8.3% ‘sometimes’ and 36.7% ‘often’ and ‘all the time’ felt strong and full of energy.

Table 5: Summary of the result of the Physical wellbeing of the children with Cerebral Palsy

Age group: 8-12 years n=60	**Never**	**Seldom**	**Sometimes**	**Often**	**All the time**
…my child felt ill	7 (11.7%)	16 (26.7%)	18 (30.0%)	12 (20.0%)	7 (11.7%)
…my child had a headache and tummy-ache	22 (36.7%)	19 (31.7%)	14 (23.7%)	3 (5.0%)	2 (3.3%)
… my child was tired and worn out	7 (11.7%)	14 (23.3%)	18 (30.0%)	14 (23.3%)	7 (11.7%)
…my child felt strong and full of energy	13 (21.7%)	20 (33.3%)	5 (8.3%)	21 (35.0%)	1 (1.7%)

Dimension 2: Emotional Well-being

Definition

This dimension examines the emotional well-being of the children with Cerebral Palsy (CP), including positive and negative emotions in different aspects of life. It specifically exposes the positive and negative perceptions and emotions experienced by the individual. The questions look at how much a child experiences positive not negative feelings, such as happiness, joy, loneliness, feeling of scared or unsure about own self.

There were 4 questions for the respondent about the emotional well-being of their children with CP. They have answered on the basis of the performance of the last week.

Table indicates that 53.6% children with CP are ‘often’ or ‘all the time’ passes the every state of life with fun and enjoyment. 61.7% respondent support ‘never’ or ‘seldom’ to answer the child’s feeling of displeasure about anything. 65% respondent support ‘never’ or ‘seldom’ to answer child’s feeling of loneliness and 28.3% respondent support ‘often or ‘all the time’ to answer this question. 40% respondent seem like their child doesn’t feel scared or unsure of him or herself and support ‘never’ and ‘seldom’. And 38.3% parent support ‘often’ or ‘all the time’ to answer about child felling of scared or unsure of him or her.

Table 6: Summary of the result of the Emotional wellbeing of the children with Cerebral Palsy

Age group: 8-12 years n=60	Never	Seldom	Sometimes	Often	All the time
…my child had fun and laughed a lot	2 (3.3%)	15 (25.0%)	11 (18.3%)	23 (38.3%)	9 (15.0%)
…my child didn’t fell much like anything	13 (21.7%)	24 (40.0%)	10 (16.7%)	6 (10.0%)	7 (11.7%)
… my child felt alone	17 (28.3%)	22 (36.7%)	4 (6.7%)	8 (13.3%)	9 (15.0%)
…my child felt scared or unsure of him or herself	8 (13.3%)	16 (26.7%)	13 (21.7%)	12(20.0%)	11(18.3%)

Dimension 3: Self- esteem

Definition

In this questionnaire self-esteem is a dimension which aimed to investigate child's feeling of success about own self. It is also examine the level of satisfaction about individual. By this section of the questionnaire it was known about the confidence level after completing any task and new experience or ideas about new things of the last week.

Respondent was answered 4 questions about the self-esteem of the children with cerebral palsy and they have answered on the basis of the performance of last week. Table 3 indicate that 53.3% respondent state tick on box of 'never' or 'seldom' to answer about the child feeling of proud of him or herself. And 46.6% responds that their child feel proud of him or her-self 'sometime' or 'often' or all the time. 46.7% participant responds that their child 'never' or 'seldom' felt on the top of the world. And 53.4% of participant think that there child felt 'sometimes' or 'often' or 'all the time' on the top of the world. 60% of respondent put tick mark on 'sometimes' or 'often' or 'all the time' to answer their child's feeling of pleasant with him or herself. 67.6% respondent indicates that 'sometime', or 'often' or 'all the time' their child had lots of good ideas.

Table 7: Summary of the result of the Self-esteem of the children with CP

Age group: 8-12 years **n=60**	**Never**	**Seldom**	**Sometimes**	**Often**	**All the time**
…my child was proud of him or herself	20 (33.3%)	12 (20.0%)	14 (23.3%)	11 (18.3%)	3 (5.0%)
…my child felt on top of the world	15 (25.0%)	13 (21.7%)	16 (26.7%)	12 (20.0%)	4 (6.7%)
… my child felt pleased with him or herself	10 (16.7%)	14 (23.3%)	24 (40.0%)	8 (13.3%)	4 (6.7%)
…my child had lots of good ideas	3 (5.0%)	18 (30.0%)	14 (23.3%)	20 (33.3%)	5 (8.3%)

Dimension 4: Family

Definition

This dimension examines the relationship of the children with CP with their parents and in the home. It explores the quality of the interaction between the children and the parents/carers, as well as the feelings of the children towards the parents/carers. Particular importance is attached to whether the children feels loved and supported by the family, whether the atmosphere at home is comfortable or otherwise, and whether the child/adolescent feels fairly treated.

Respondent was answered 4 questions about the self-esteem of the children with cerebral palsy and they have answered on the basis of the performance of last week.

Table shows that 96.6% respondent state that felt well with the parent and put tick mark on ‘often’ or ‘all the time’. 88.3% respondent state that their child felt fine at home and put tick mark on ‘often’ or ‘all the time’. 41.7% respondent indicates that they quarreled at home ‘never’ or ‘seldom’. 41.7% respondent state that ‘sometimes’ they are quarreled at home. 71.6% respondent state that their child felt that their parent was bossing him or her around.

Table 8: Summary of the result of the family dimension of the children with CP

Age group: 8-12 years n=60	Never	Seldom	Sometimes	Often	All the time
…my child got on well with us as parent	-	-	2 (3.3%)	14 (23.3%)	44 (73.3%)
…my child felt fine at home	-	1 (1.7%)	6 (10.0%)	17 (28.3%)	36 (60%)
…we quarreled at home	7 (11.7%)	18 (30.0%)	25 (41.7%)	9 (15.0%)	1 (1.7%)
…my child felt that I was bossing him/ her around	2 (3.3%)	15 (25.0%)	26 (43.3%)	11 (18.3%)	6 (10.0%)

Dimension 5: Social Contact

Definition

This dimension examines the nature of the relationships of the children with CP with the other children and it considers the social relations with friends and peers. The dimension explores the quality of the interaction between the children and their peers. The questions examine the extent to which the children feel accepted and supported by friends and their ability to form and maintain friendships. And it also examined the feeling of the children to investigate whether or not that is different from other children.

Respondent was answered 4 questions about the social contact of the children with cerebral palsy and they have answered on the basis of the performance of last week. Table indicate that 65% respondent report that 'sometimes' or 'often' or 'all the time' their children did different activities with their friends. 70% respondents reports that their children was liked by other and put tick marks on the 'sometimes' or 'often' or 'all the time' where 30% respondent reported 'never' or 'seldom'. 83.4% respondent indicate that their children got along well with his or her friend and put tick mark on 'sometimes' or 'often' or 'all the times'. From 46.6% respondent some are state about their children 'never' felt different from other children and some other reported that their children 'seldom' felt different from the other children. And 53% respondent state that their children felt different from other children and put tick mark on 'sometimes' or 'often' or 'all the time'.

Table 9: Summary of the result of the Social- contact of the children with Cerebral Palsy

Age group: 8-12 years n=60	Never	Seldom	Sometimes	Often	All the time
…my child did things together with friends	9 (15.0%)	12 (20.0%)	9 (15.0%)	15 (25.0%)	15 (25.0%)
…my child was liked by other kids	2 (3.3%)	16 (26.7%)	10 (16.7%)	12 (20.0%)	20 (33.3%)
…my child got along well with his or her friend	4 (6.7%)	6 (10.0%)	7 (11.7%)	9 (15.0%)	34 (56.7%)
…my child felt different from other children	2 (3.3%)	26 (43.3%)	11 (18.3%)	7 (11.7%)	14 (23.3%)

Dimension 6: School

Definition

This dimension of the questionnaire examined the parent understanding of their children’s feeling about their school to find out whether or not their children enjoyed the school lesion. To find out the coping skills with the school works. This dimension also examined child’s feeling of worries about their future. It is also investigate those children whether or not afraid of bad marks or grades.

Respondent was answered 4 questions about the school of the children with cerebral palsy and they have answered on the basis of the performance of last week of these children.

Table shows, 68.4% respondent report that their children easily coped with the school work and put mark on ‘sometimes’ or ‘often’ or ‘all the time’. And 31.6% reported that their children ‘never’ or ‘seldom’ coped with the school work. 83.3% respondent indicate that their children school lesson and put tick mark on ‘sometimes’ or ‘often’ or ‘all the time’. 68.3% respondent report that their child are ‘sometimes’ or ‘often’ or ‘all the time’ worried about his or her future. 68.4% respondent indicate that their child was afraid ‘sometimes’ or ‘often’ or ‘all the time’ of bad marks or grades.

Table 10: Summary of the result of the School dimension of the children with Cerebral Palsy

Age group: 8-12 years n=60	Never	Seldom	Sometimes	Often	All the time
…my child easily coped with school work	2 (3.3%)	17 (28.3%)	7 (11.7%)	27 (45.0%)	7 (11.7%)
…my child enjoyed the school lessons	1 (1.7%)	9 (15.0%)	12 (20.0%)	27 (45.0%)	11 (18.3%)
… my child worried about his or her future	9 (15.0%)	10 (16.7%)	23 (38.3%)	12 (20.0%)	6 (10.0%)
…my child was afraid of bad marks or grades	9 (15.0%)	10 (16.7%)	22 (36.7%)	16 (26.7%)	3 (5.0%)

Dimension 7: Disease Module

Definition

This dimension of the questionnaire examined child's feeling of afraid that he might get worse. It will also examined whether or not children's ability to cope well with his or her illness. This section will find out that parent of children with CP was treated or not treated because of their illness. This examined whether or their child avoided other to notice his or her illness.

Respondent was answered 4 questions about the disease module of the children with cerebral palsy and they have answered on the basis of the performance of last week of these children.

60.1% respondent indicate that their children was afraid that the illness might get worse and put tick mark on 'sometimes', or 'often', or 'all the time'. 56.7% respondent state that their children was sad because of the illness and put tick mark on 'sometimes', or 'often', or 'all the time'. 67.7% of participant state that their children are able to cope 'sometimes' or 'often' or 'all the time' with his or her illness. 91.6% respondent state that they are treated their children though he or she was younger, because of the illness. 66.6% respondent report 'never' or 'seldom' to answer about child's tendency to avoid other to notice his or her illness. 88.3% respondent report 'never' or 'seldom' to answer child's tendency to miss something at school because of his or her illness.

Table 11: Summary of the result of the disease Module of the children with Cerebral Palsy

Age group: 8-12 years n=60	Never	Seldom	Sometimes	Often	All the time
…my child was afraid that the illness might get worse	10 (16.7%)	14 (23.3%)	22 (36.7%)	10 (16.7%)	4 (6.7%)
…my child was sad because of the	6 (10.0%)	20 (33.3%)	12 (20.0%)	15 (25.0%)	7 (11.7%)

illness					
… my child was able to cope well with his or her illness	1 (1.7%)	18 (30.0%)	22 (36.7%)	16 (26.7%)	3 (5.0%)
…We treated our child as though he or she were younger, because of the illness	2 (3.3%)	3 (5.0%)	14 (23.3%)	3 (5.0%)	38 (63.3%)
…my child avoided other to notice his or her illness	29 (48.3%)	11 (18.3%)	6 (10.0%)	8 (13.3%)	6 (10.0%)
…my child missed something at school because of his or her illness	42 (70.0%)	11 (18.3%)	4 (6.7%)	-	3 (5.0%)

4.3. Result of the Participation of the Self-Care activities: Life Habit

Table -12: Summary of the result of the Participation of the Self- Care Activities

Score	Gender		Total
	Male	Female	
.01-5 **(Poor performance)**	27 (71.1%)	16 (64.0%)	43 (71.7%)
(5-10) **(Good performance)**	8 (22.9%)	9 (36.0%)	17 (28.3%)
	35	25	n= 60

Table- 12, shows that among the 25 female children with Cerebral Palsy 16 (64.0%)

was scored 0 to 5 and 9 (36.0%) was scored 5.1 to 10. Otherwise, among the 35 children with cerebral palsy (boys), 27 (77.1%) children get score from 0 to 5 and 8 (22.9%) children was scored from 5.1 to 10.

Pearson correlation has done to investigate whether or not there have any association between participation of self-care activities and gender. And in this correlation test p value is .265 which is greater than .005 so there is not a significant relation between the gender and participation.

And the result also shows that 71.7% participant state that the participation level of self-care activities their children is 0-5. And 28.3% participant state that the participation level of self-care activities their children is 5.1- 10. In both gender maximum participation level in self-care activities is poor.

4.4. Result of correlation between participation of the self-care activities and each dimension of the QOL:

A Pearson product-moment correlation coefficient was computed to assess the relationship between the self-care activities of Life Habit scale and six dimension of the quality of life scale. Shown below the result of the correlation between these two variables:

Table 13: Summary of the result of the correlation between QOL and Life Habit score of self- care activities:

Sub-scale of QOL	Life Habit Score of self- care activities	P- value
Physical Well-being	-.411	.001
Emotional Well-being	-.517	.000
Self- esteem	.739	.000
Family	.007	.955
Social Contact	.544	.000
School	.382	.003
Long time illness	-.211	.106

4.4.1. Correlation between participation of the self-care activities and physical well-being of the quality of life (QOL):

There was a negetive correlation between the self-care activities and physical well-being of the quality of life (QOL), r = -.411, n = 60, p = 0.001. A scatter plot summarizes the results (Figure-1) Overall, there was not any strong negative correlation between self- care activities and physical well-being. That mean increases the score of self- care activities is not strongly correlated with the decrease the score of physical well-being dimension of the QOL.

4.4.2. Correlation between participation of the self-care activities and emotional well-being dimension of the QOL:

Negative correlation was found between the self-care activities and emotional well-being dimension of the QOL, r = -.517, n=60, p = 0.000. A scatter plot summarizes the results (Figure- 2).In total, it shows that there was not any strong negative correlation between self- care activities and emotional well-being. That mean increases the score of self- care activities is not strongly correlated with the decrease the score of physical well-being dimension of the QOL**.**

4.3.3. Correlation between participation of the self-care activities and self- esteem dimension of the QOL:

There was a positive correlation between the self-care activities and self- esteem dimension of the QOL, r = 0.739, n = 60, p = 0.000. A scatter plot summarizes the results (Figure-3) Overall, there was a strong, positive correlation between the self-care activities and self- esteem dimension of the QOL. Which mean increases in self-care activities were strongly correlated with increases in self-esteem dimension of the QOL.

4.3.4. Correlation between participation of the self-care activities and family dimension of the QOL:

There was a positive correlation between the self-care activities and family dimension of the QOL: r = 0.007, n = 60, p = 0.955. A scatter plot summarizes the results (Figure-4). Overall, there was a very weak, positive correlation between the self-care activities and self- esteem dimension of the QOL. Which mean increases in self-care activities were not strongly correlated with increases in family dimension of the QOL.

4.3.5. Correlation between participation of the self-care activities and Social contact dimension of the QOL:

A positive correlation was found between the two variables, r = 0.544, n = 60, p = 0.106. A scatter plot summarizes the results (Figure-5). Overall, there was a strong, positive correlation between the self-care activities and social contact dimension of the QOL. Which mean increases in self-care activities were strongly correlated with increases in social contact dimension of the QOL.

4.3.6. Correlation between participation of the self-care activities and School dimension of the QOL:

There was a positive correlation between the two variables, r = 0.382, n = 60, p = 0.003. A scatter plot summarizes the results (Figure- 5). Overall, there was positive correlation between the self-care activities and social contact dimension of the QOL which is not so strong. Which mean increases in self-care activities were correlated with increases in school dimension of the QOL.

4.3.7. Correlation between participation of the self-care activities and Disease module dimension of the QOL:

A negative correlation was found between the self-care activities and disease module dimension of the QOL, r = -0.211, n = 60, p = 0.106. A scatter plot summarizes the results (Figure-7). Overall, there was negative correlation between the self-care activities and disease module dimension of the QOL which is not so strong. Which mean increases in self-care activities were not correlated with increases in school dimension of the QOL.

4.4.1. Result of correlation through the graph (scatter plot):

1) Participation in self -care activities vs. physical well being

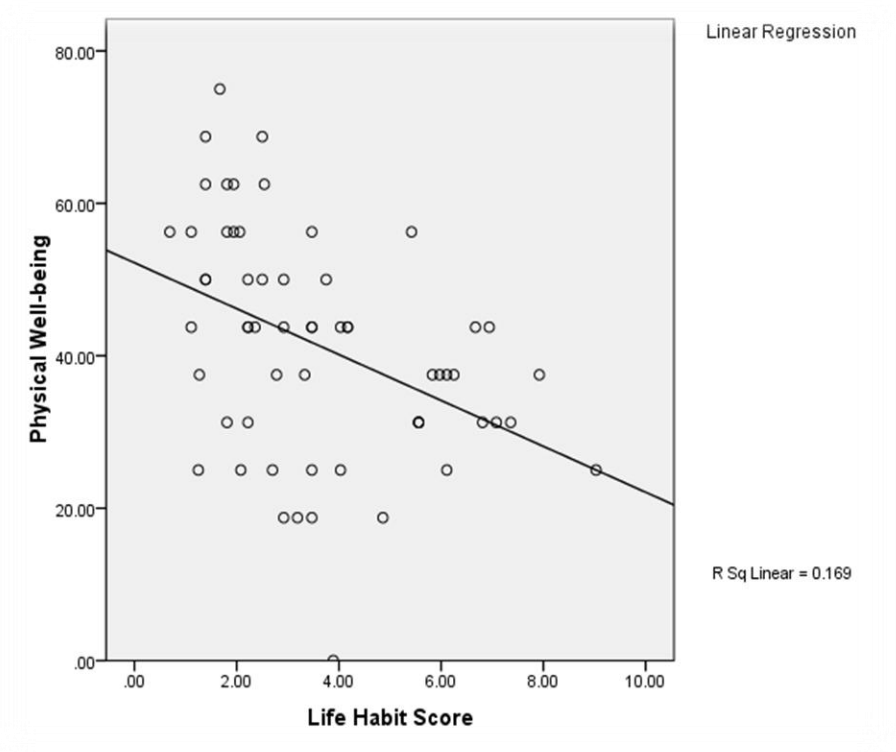

Figure 1: There is a negative correlation (imaginary line slope down) between two variables (e.g. participation of self- care activities of life habit score and the physical well-being of quality of life score). Which means there is a correlation but one value goes down as the other value increases.

2) Participation in Self -care Activities vs. Emotional well being

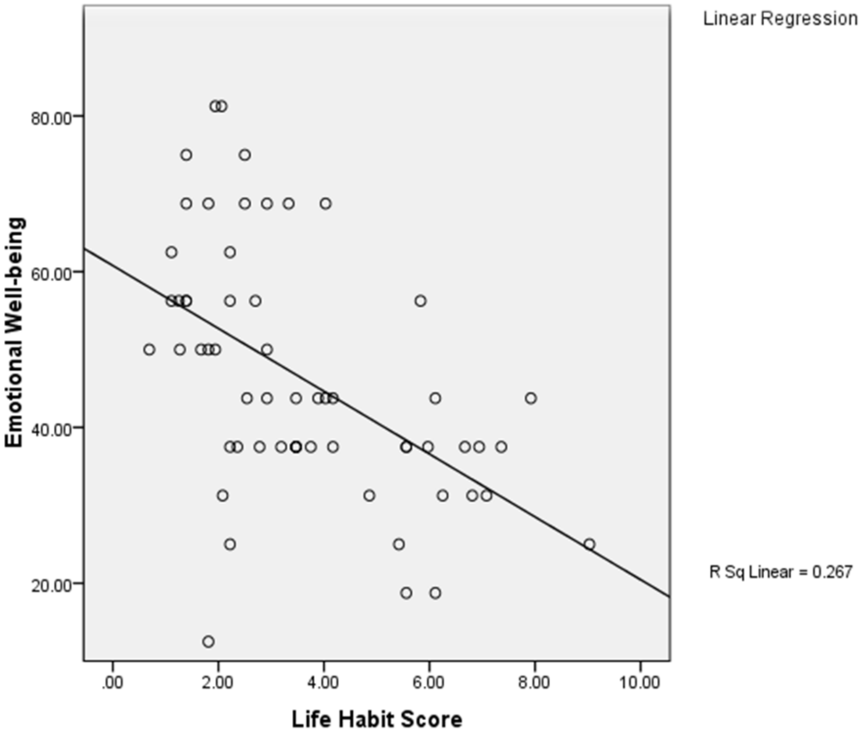

Figure 2: It shows the negative correlation (imaginary line slope down) between two variables (e.g. participation of self- care activities of life habit score and the emotional well-being of quality of life score). This means there is a correlation where one value goes down as the other value increases.

3) Participation in self -care activities vs. Self- esteem

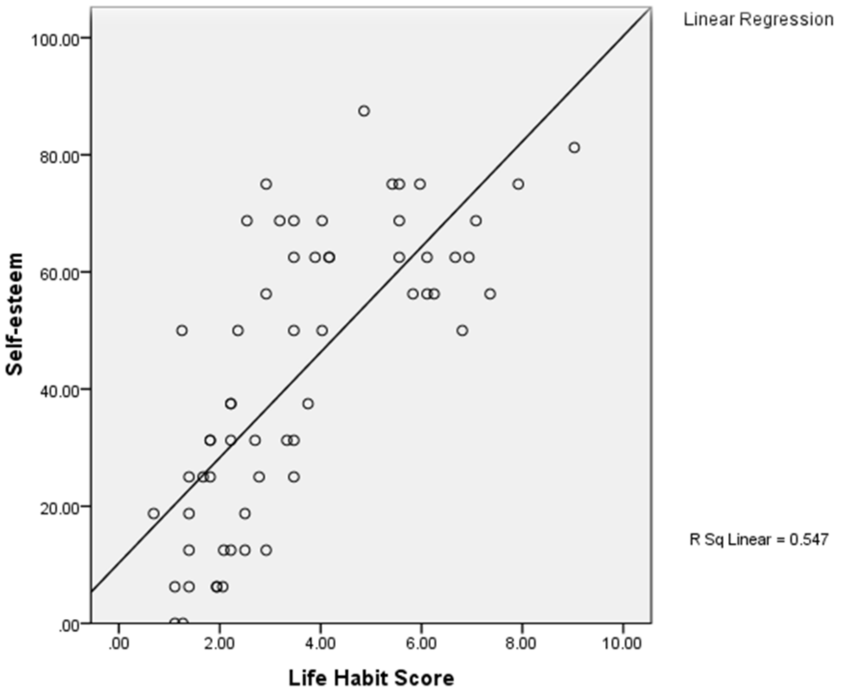

Figure 3: It shows the strong and positive correlation (imaginary line slope down) between two variables (e.g. participation of self- care activities of life habit score and the self-esteem of quality of life score). This means there is a correlation where one value increase as the other value increases.

4) Participation in self -care activities vs. Family

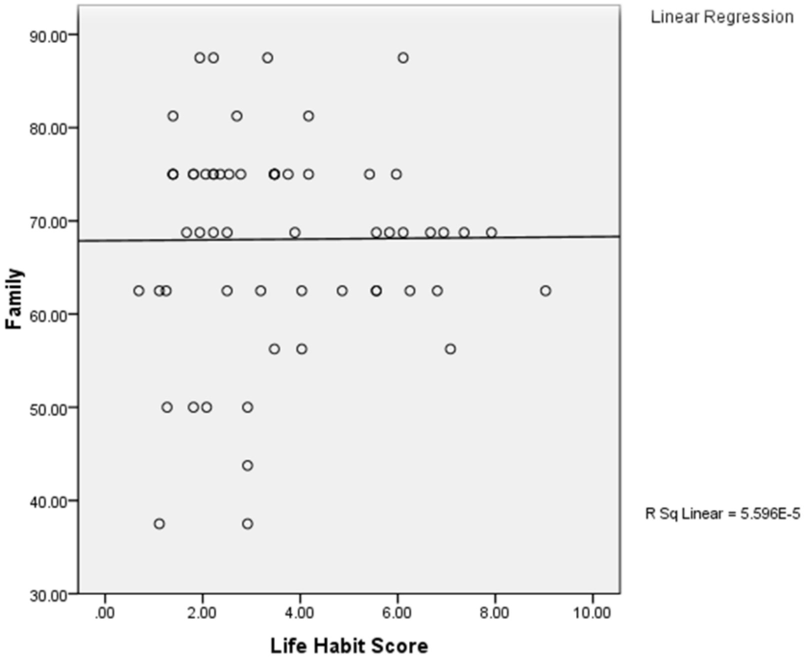

Figure-4: There have no correlation between life habit score and family.

5) Participation in self -care activities vs. Social Contact

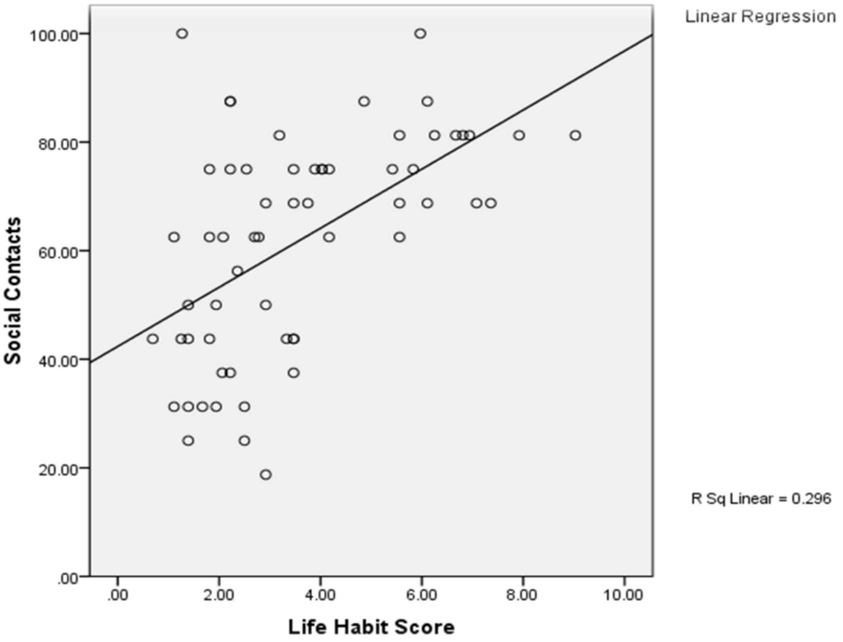

Figure- 5: There have positive correlation between Life habit score and social contact where a value increase as other value increase.

6) Participation in self -care activities vs. School

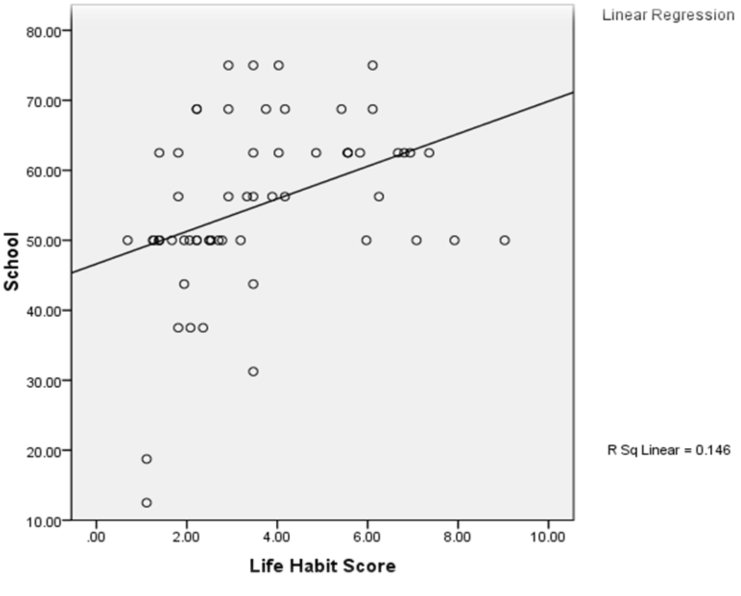

Figure-6: There have correlation between the life habit score and school which is not so strong where one value is increase as other value is increase.

7) Participation in self -care activities vs. long time illness

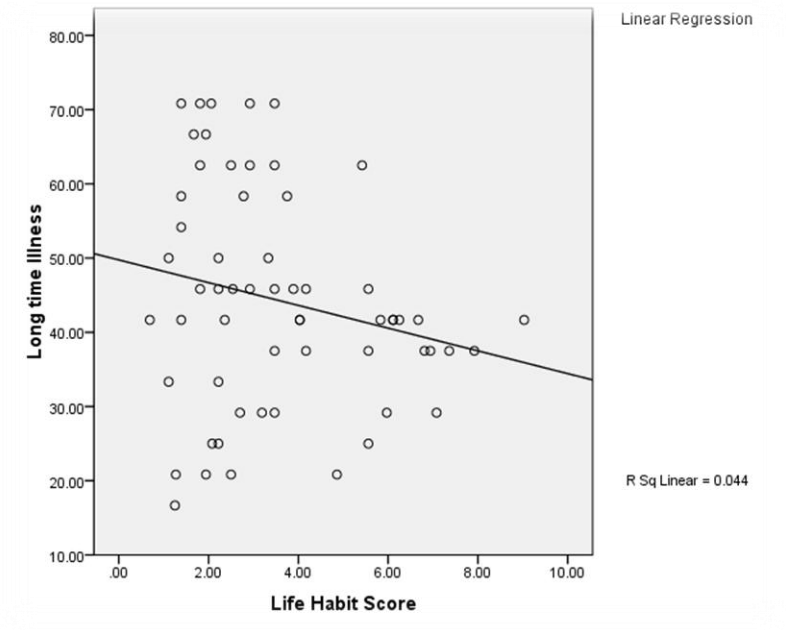

Figure-7: there is a negative correlation between life habit and long-time illness where one value is increase as other value decrease.

Chapter-5: Discussion

5.1. Discussion: Dimension of Quality of Life (QOL)

5.1.1. Dimension: Physical wellbeing

‘Physical wellbeing’ is first dimension of the KINDL questionnaire for measuring the QOL where participant answered different 4 questions. In this study, table-5 shows67.70% participant state that their child felt ill ‘sometimes’ or ‘often’ or ‘all the time’. Another study about the QOL of CP children shows that 95% of all the respondents felt that their child’s health was ‘good’, ‘very good’ or ‘excellent’ instead of respectively ‘sometimes’ or ‘often’ or ‘all the time’ (Keenaghan and Kilroe 2008). To answer about the child’s feeling of strength and full of energy, 55% respondent state that their children with CP feel energy and strength which is ‘poor’ or ‘fair’ instead of ‘never’ or ‘seldom’. A further study indicate that 11% children of the respondent felt ‘poor’ or ‘fair’ full of energy (Keenaghan and Kilroe 2008).And comparatively the physical well-being status of the children with CP of these school of the Dhaka city is poor rather than children with CP of the Irish children.

This study measures the mean score of physical wellbeing which is 41.35. Where another study about QOL of children with CP state the mean score of physical wellbeing which is 67.02 (Keenaghan and Kilroe 2008).Other study which is also aimed to find out QOL indicate their participant’s physical wellbeing score is about 55 (Arnaud et al 2008).

5.1.2 Dimension: Emotional Wellbeing

In the context of Bangladesh this study shows that 71.9% children with CP are ‘sometimes’ or ‘often’ or ‘all the time’ pass time with fun and enjoyment (Table- 6). Where another shows, 78% reported that they have ‘very often’ or ‘always’ had fun (Keenaghan and Kilroe 2008).

In this study the mean of the emotional well-being is 46.25 where another study regarding QOL of children with CP shows the mean score 75.45 (Keenaghan and Kilroe 2008). A study about ‘QOL of Children with Cerebral Palsy in Europe’ report a mean score of the emotional wellbeing which is 77.9% (Arnaud et al 2008).The score of the emotional wellbeing of the children with CP of these school of Dhaka is comparatively less than other study of the QOL.

5.1.3. Dimension: Self- esteem

In this study Self-esteem of the children with Cerebral Palsy has measured where mean score is 42.70 which is based on the context of the Bangladesh (Table- 7). Where another study in Europe about QOL of Children with Cerebral Palsy shows the mean score is 77.9 (Arnaudet al. 2008). One other study about the QOL of children with CP state 62.51 mean score of these children with CP (Keenaghan and Kilroe 2008).

5.1.4. Dimension: Family

In this study the result of the family dimension shows that 96.6% parent state that their children enjoyed at home. 88.3% respondent state that their child felt fine at home (Table- 8). In the context of Bangladesh the mean score for this dimension is 68.02. And another study about similar subject of European context state about mean which is 75.39 (Keenaghan and Kilroe 2008) which is nearly similar of 76.9 and this study is also in European context (Arnaud et al 2008).

5.1.5. Dimension: Social Contact

Table- 9 shows that 65% respondent report that their children were engaged with the different activities with their friends. 70% respondents reports that their children was liked by other where 30% respondent reported ‘never’ or ‘seldom’. 83.4%respondent indicates that their children got along well with his or her friend. And this study has state the mean score for social contact dimension which is 62.7. There have two study about the QOL of CP children where one study shows 49.1 and 77.17 (Keenaghan and Kilroe 2008; Arnaudet al 2008). This result shows that the self-esteem dimension of the children with CP of those schools of the Dhaka city is improved than one other study of Keenaghan and Kilroe. And nearer to the study of Arnaud which was about the QOL of the children with CP.

5.1.6. Dimension: School

68.4% respondent report that their children easily coped with the school work for ‘sometimes’ or ‘often’ or ‘all the time’. 31.6% reported that their children coped with the school work. 83.3% respondent indicates that their children enjoyed school lesson. 68.3% respondent report that their children are worried about his or her future. In this study the mean score of this dimension is 55 in the context of Bangladesh. Another study about the QOL of the children with CP, where mean score is 62.60 (Keenaghan and Kilroe 2008) and this study is the context of Europe. There has one more study about the QOL of CP, which shows the mean is 72.0 (Arnaud, C. et al 2008).

5.1.7. Dimension: Disease Module

About 56.7% respondent states that their children were sad because of the illness. 67.7% of participant state that their children are able to cope with his or her illness. 91.6% respondent state that they are treated their children though he or she was younger, because of the illness. 66.6% respondent report to answer about child's tendency to avoid other to notice his or her illness. 88.3% respondent report 'never' or 'seldom' to answer child's tendency to miss something at school because of his or her illness. There have lack of literature to compare with the findings.

5.2. Discussion: participation of the self-care activities of Children with Cerebral Palsy

One study about the participation of the children with CP has shown that boys are more in number than girls (Manus et al 2008). Where the findings of the study shows that there have 35 male and 25 female (Table- 4). One study was measured the overall participation in everyday activities and shows that girls had a marginally higher score than boys (mean: 47.3 v 46.2) (Manus et al 2008). And the findings of the study are nearly similar (Table -12).

5.3. Correlation between Life habit score (participation in self-care activities) and Quality of Life of children with Cerebral Palsy

This study present that there have strong correlation of self-esteem, social contact, school with the participation of the self-care activities. That mean if the self-esteem, social contact, school are improved which may associated with the improved participation in self –care activates where the p value is respectively .000, .000 and .003 ($p<.005$) (Table- 13). One study about the correlation between the QOL and participation of the self-care activities was shown that participation in everyday activities was significantly associated with quality of life in 3 of the 10 domains and these domains are physical well-being, social support and peers & moods and emotions (Manus et al 2008).

Another study about the aim to find out the correlation between the QOL and participation of the self- care activities was shows that: For parent proxy-report, all domains of QOL were significantly associated with functioning level (Shellyet al. 2008).For child self-report, feelings about functioning, participation and physical health, and pain and feelings about disability, were significantly associated with functioning level. Physical type domains of QOL accounted for more of the variance in functioning than psychosocial type domains. Children with CP have the potential to report a high psychosocial QOL score even if they have poor functioning (Shelly 2008).

This study is not examined the self-reported QOL of the children with the CP and similarly this study shows that social contact has significant correlation with the participation of the self-care activities (Table- 13).

Physical and emotional wellbeing with the long time illness dimension of QOL is also associated with the participation of the self-care activates. The result of the study has shown that the correlation was not always in positive direction (Figure- 1, 2 7). Which mean that if one variable (Physical wellbeing, emotional wellbeing and longtime illness) is increased against the variable (participation of the self-care activities) is decreased where p values are respectively .000, .001, 106 ($p<.005$) (Table-13). And there family hasn’t significant correlation with the participation of the self-care activities. The low Physical well-being and Social support and peers domains means that the parents of these children think the children are lonely and find it difficult to make friends and communicate with their peers (Manus, V. M. et al 2008). This research will not change attitudes towards young people with CP. But could facilitate access to an improved social life by raising the awareness that they are lonely and do have physical impairments that stop them from getting places. Adaptations could improve their quality of life even further (Manus et al 2008).

Chapter-6: Limitation and Recommendation

6.1. Limitation of the study:

- This study has conducted only 60 samples. Which not represent the total population of the children with cerebral palsy. So the result of the study isn't applicable for the total population.
- As it is a school based study, so children who are going to school they only get access to be sample for the study. But school-based research does not reach children who are not in school.
- The sample was taken from a defined geographical area where the same services were available to the families of the CP children. Carrying out such a study on a national basis would have resulted in a more representative sample in the context of varied services.
- This is parent reported Quality of Life of the children with Cerebral Palsy (CP) where many confounding factor may affect the opinion of the parent like stress. This is not examined in this study.
- Research schedules were enforced by the school timetable, school holidays and examinations. Absence of children due to illness may cause of difficulty in data collection by which more time was needed in completing data collection.

6.2. Recommendations

There have lack of enough resource about the quality of life and participation in the Life Habit skills of the children with Cerebral Palsy. So these studies are recommended below:

- Association between quality of life and level of impairment of the children with cerebral palsy with the large number of sample.
- Influence of the participation of the life habit skills on the quality of life of children with cerebral palsy with large number of sample group.
- Comparison of the quality of life between children with CP and children without CP.
- In addition further study is needed include the treatment strategies for improving the quality of life of the children with CP.
- Further study about the level of stress of the parent with the correlation of the QOL of the children with CP.

6.3. Conclusion

Today's time Quality of Life (QOL) of Children with Cerebral Palsy (CP) is an important and interesting field of investigation. But in Bangladesh there have lack of literature about the QOL of the children with CP. Where this study was aimed to find out the relationship between participation of the self-care activities and QOL of children with CP. The Dimension of QOL was physical well-being, emotional well-being, self-esteem, family, friends, school and longtime illness to measure the QOL. And there have different activities for assessing the performance of the self-care activities like: personal hygiene, toileting dressing, maintenance of assistive device, taking part in personal health care and using service provided by medical clinic, hospital or rehabilitation centre etc. Findings of the study shows the importance of asking families about different aspects of their child's QOL and especially when the child has associated impairment in participation. Because the results of the study support that there have a relationship between the participation in the self-care activities and the QOL of the children with Cerebral palsy. From the result of the study it is shown that self-esteem, social contact and school is significantly correlated in positive direction. And the result of the comparison with the other study has shown that the children with CP of these schools has a lower quality of life rather than the children with the CP of the European country. Although this study has showed that the physical and emotional well-being is negatively correlated with the participation of the self-care activities but literature give strong emphasis on correlation of these two result. For that reasons, more population specific measures have to be developed for in-depth analysis of these factors. Though there have many limitations in this study but the result has the contribution toward an understanding of the levels of participation and quality of life of children living with CP in these selected schools of the Dhaka city of Bangladesh.

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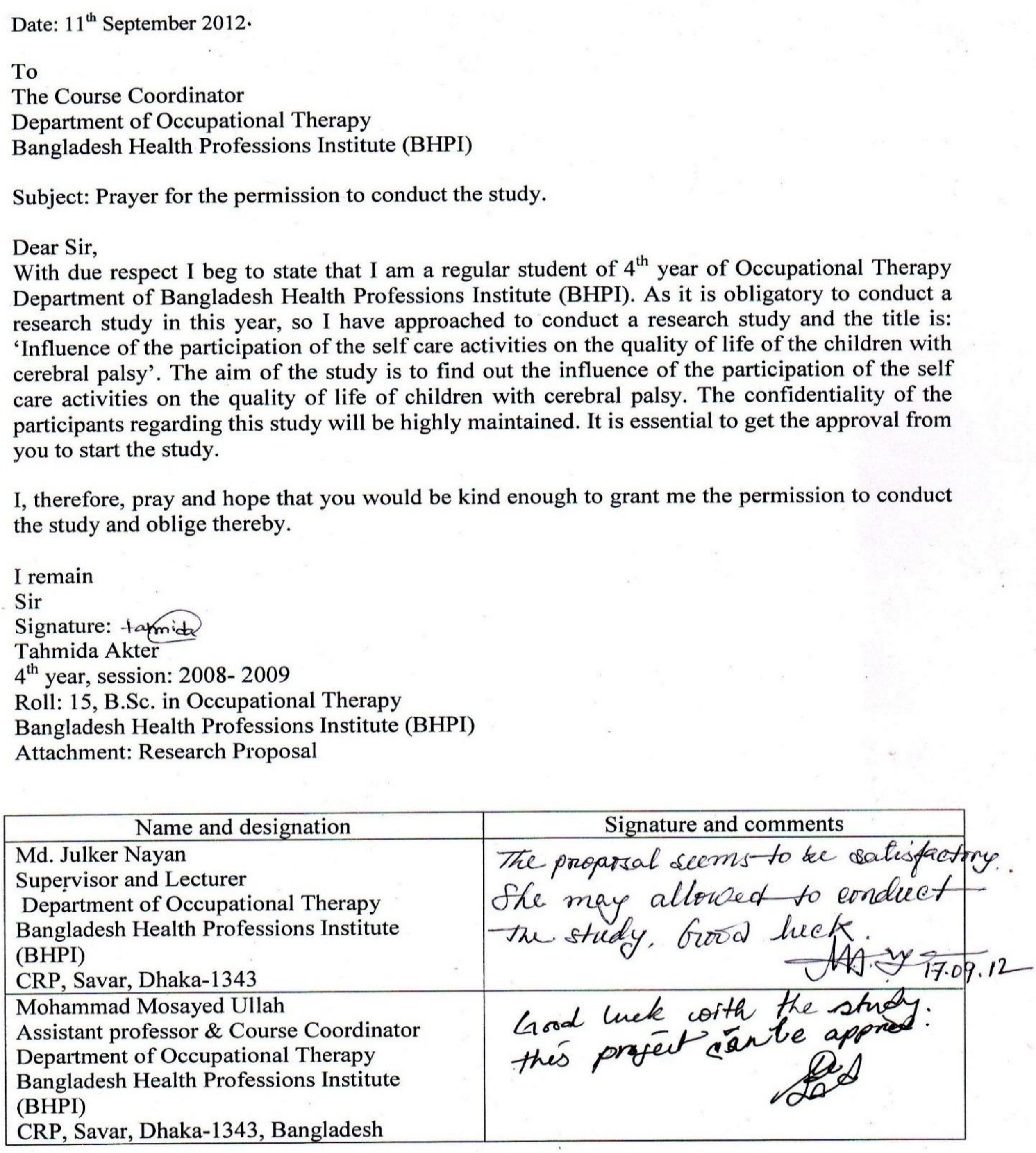
Appendix: 1 (Approval Letter from the BPHI)



Date: 11th September 2012.

To
The Course Coordinator
Department of Occupational Therapy
Bangladesh Health Professions Institute (BHPI)

Subject: Prayer for the permission to conduct the study.

Dear Sir,
With due respect I beg to state that I am a regular student of 4th year of Occupational Therapy Department of Bangladesh Health Professions Institute (BHPI). As it is obligatory to conduct a research study in this year, so I have approached to conduct a research study and the title is: 'Influence of the participation of the self care activities on the quality of life of the children with cerebral palsy'. The aim of the study is to find out the influence of the participation of the self care activities on the quality of life of children with cerebral palsy. The confidentiality of the participants regarding this study will be highly maintained. It is essential to get the approval from you to start the study.

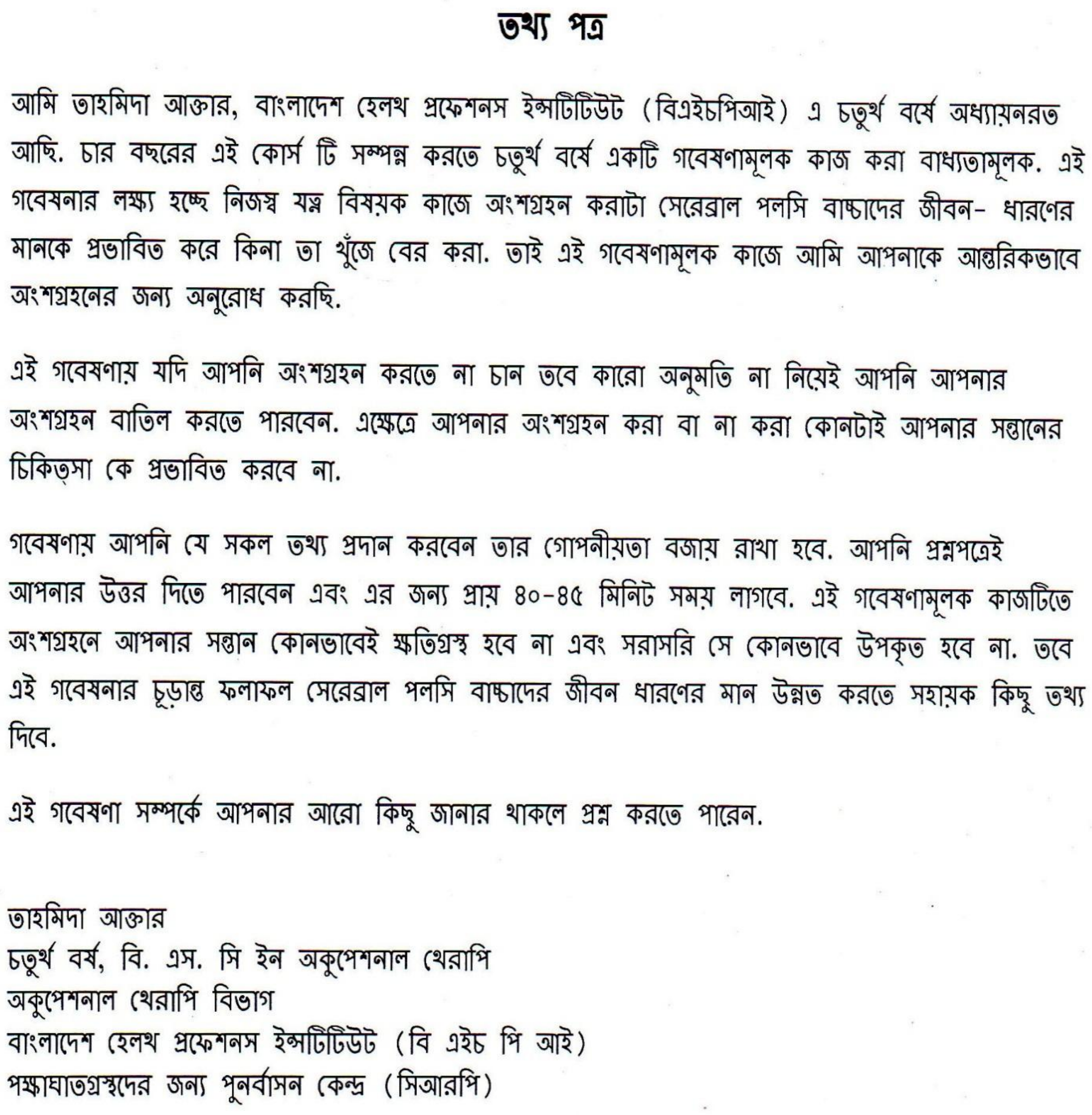
I, therefore, pray and hope that you would be kind enough to grant me the permission to conduct the study and oblige thereby.

I remain
Sir
Signature: tahmida
Tahmida Akter
4th year, session: 2008- 2009
Roll: 15, B.Sc. in Occupational Therapy
Bangladesh Health Professions Institute (BHPI)
Attachment: Research Proposal

Name and designation	Signature and comments
Md. Julker Nayan Supervisor and Lecturer Department of Occupational Therapy Bangladesh Health Professions Institute (BHPI) CRP, Savar, Dhaka-1343	The proposal seems to be satisfactory. She may allowed to conduct the study. Good luck. 17.09.12
Mohammad Mosayed Ullah Assistant professor & Course Coordinator Department of Occupational Therapy Bangladesh Health Professions Institute (BHPI) CRP, Savar, Dhaka-1343, Bangladesh	Good luck with the study: this project can be approved:

Appendix- 2 (Information Sheet for the Respondent)

(গবেষনায় অংশগ্রহণকারীদের জন্য তথ্য পত্র)



তথ্য পত্র

আমি তাহমিদা আক্তার, বাংলাদেশ হেলথ প্রফেশনস ইন্সটিটিউট (বিএইচপিআই) এ চতুর্থ বর্ষে অধ্যায়নরত আছি. চার বছরের এই কোর্স টি সম্পন্ন করতে চতুর্থ বর্ষে একটি গবেষণামূলক কাজ করা বাধ্যতামূলক. এই গবেষনার লক্ষ্য হচ্ছে নিজস্ব যত্ন বিষয়ক কাজে অংশগ্রহন করাটা সেরেব্রাল পলসি বাচ্চাদের জীবন- ধারণের মানকে প্রভাবিত করে কিনা তা খুঁজে বের করা. তাই এই গবেষণামূলক কাজে আমি আপনাকে আন্তরিকভাবে অংশগ্রহনের জন্য অনুরোধ করছি.

এই গবেষণায় যদি আপনি অংশগ্রহন করতে না চান তবে কারো অনুমতি না নিয়েই আপনি আপনার অংশগ্রহন বাতিল করতে পারবেন. এক্ষেত্রে আপনার অংশগ্রহন করা বা না করা কোনটাই আপনার সন্তানের চিকিত্‌সা কে প্রভাবিত করবে না.

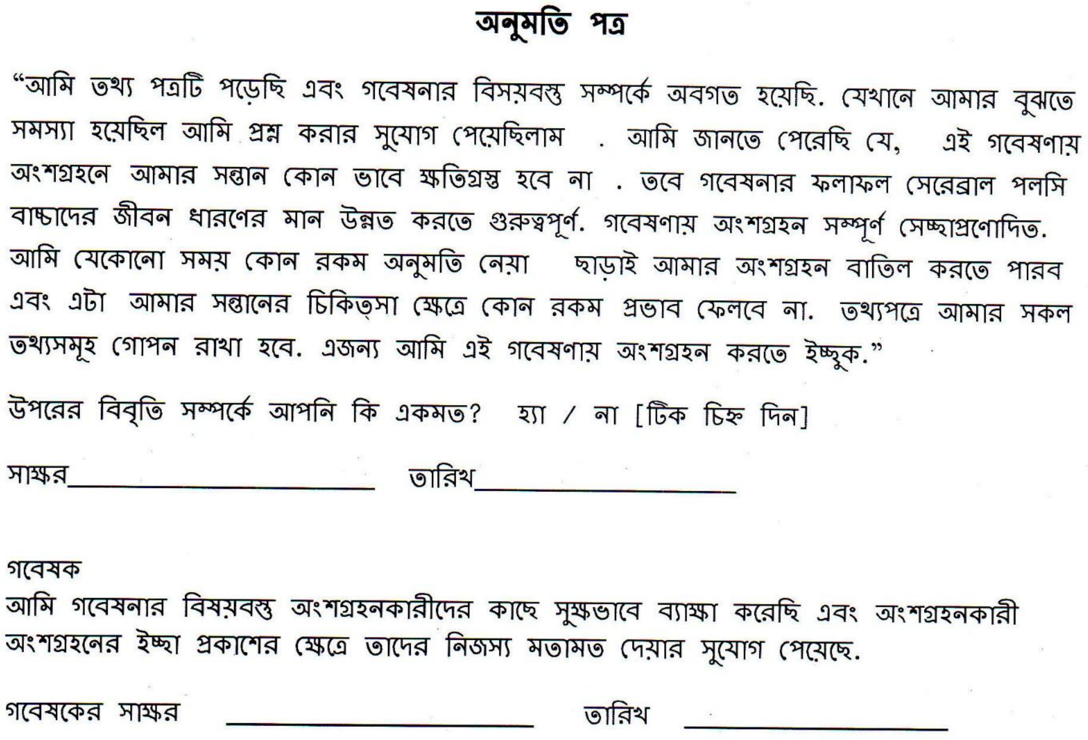
গবেষণায় আপনি যে সকল তথ্য প্রদান করবেন তার গোপনীয়তা বজায় রাখা হবে. আপনি প্রশ্নপত্রেই আপনার উত্তর দিতে পারবেন এবং এর জন্য প্রায় ৪০-৪৫ মিনিট সময় লাগবে. এই গবেষণামূলক কাজটিতে অংশগ্রহনে আপনার সন্তান কোনভাবেই ক্ষতিগ্রস্থ হবে না এবং সরাসরি সে কোনভাবে উপকৃত হবে না. তবে এই গবেষনার চূড়ান্ত ফলাফল সেরেব্রাল পলসি বাচ্চাদের জীবন ধারণের মান উন্নত করতে সহায়ক কিছু তথ্য দিবে.

এই গবেষণা সম্পর্কে আপনার আরো কিছু জানার থাকলে প্রশ্ন করতে পারেন.

তাহমিদা আক্তার
চতুর্থ বর্ষ, বি. এস. সি ইন অকুপেশনাল থেরাপি
অকুপেশনাল থেরাপি বিভাগ
বাংলাদেশ হেলথ প্রফেশনস ইন্সটিটিউট (বি এইচ পি আই)
পক্ষাঘাতগ্রস্থদের জন্য পুনর্বাসন কেন্দ্র (সিআরপি)

Appendix- 3: Information Sheet for the Respondent

(গবেষনায় অংশগ্রহণকারীদের জন্য অনুমতি পত্র)



অনুমতি পত্র

"আমি তথ্য পত্রটি পড়েছি এবং গবেষনার বিসয়বস্তু সম্পর্কে অবগত হয়েছি. যেখানে আমার বুঝতে সমস্যা হয়েছিল আমি প্রশ্ন করার সুযোগ পেয়েছিলাম . আমি জানতে পেরেছি যে, এই গবেষণায় অংশগ্রহনে আমার সন্তান কোন ভাবে ক্ষতিগ্রস্ত হবে না . তবে গবেষনার ফলাফল সেরেব্রাল পলসি বাচ্চাদের জীবন ধারণের মান উন্নত করতে গুরুত্বপূর্ণ. গবেষণায় অংশগ্রহন সম্পূর্ণ সেচ্ছাপ্রণোদিত. আমি যেকোনো সময় কোন রকম অনুমতি নেয়া ছাড়াই আমার অংশগ্রহন বাতিল করতে পারব এবং এটা আমার সন্তানের চিকিত্সা ক্ষেত্রে কোন রকম প্রভাব ফেলবে না. তথ্যপত্রে আমার সকল তথ্যসমূহ গোপন রাখা হবে. এজন্য আমি এই গবেষণায় অংশগ্রহন করতে ইচ্ছুক."

উপরের বিবৃতি সম্পর্কে আপনি কি একমত? হ্যা / না [টিক চিহ্ন দিন]

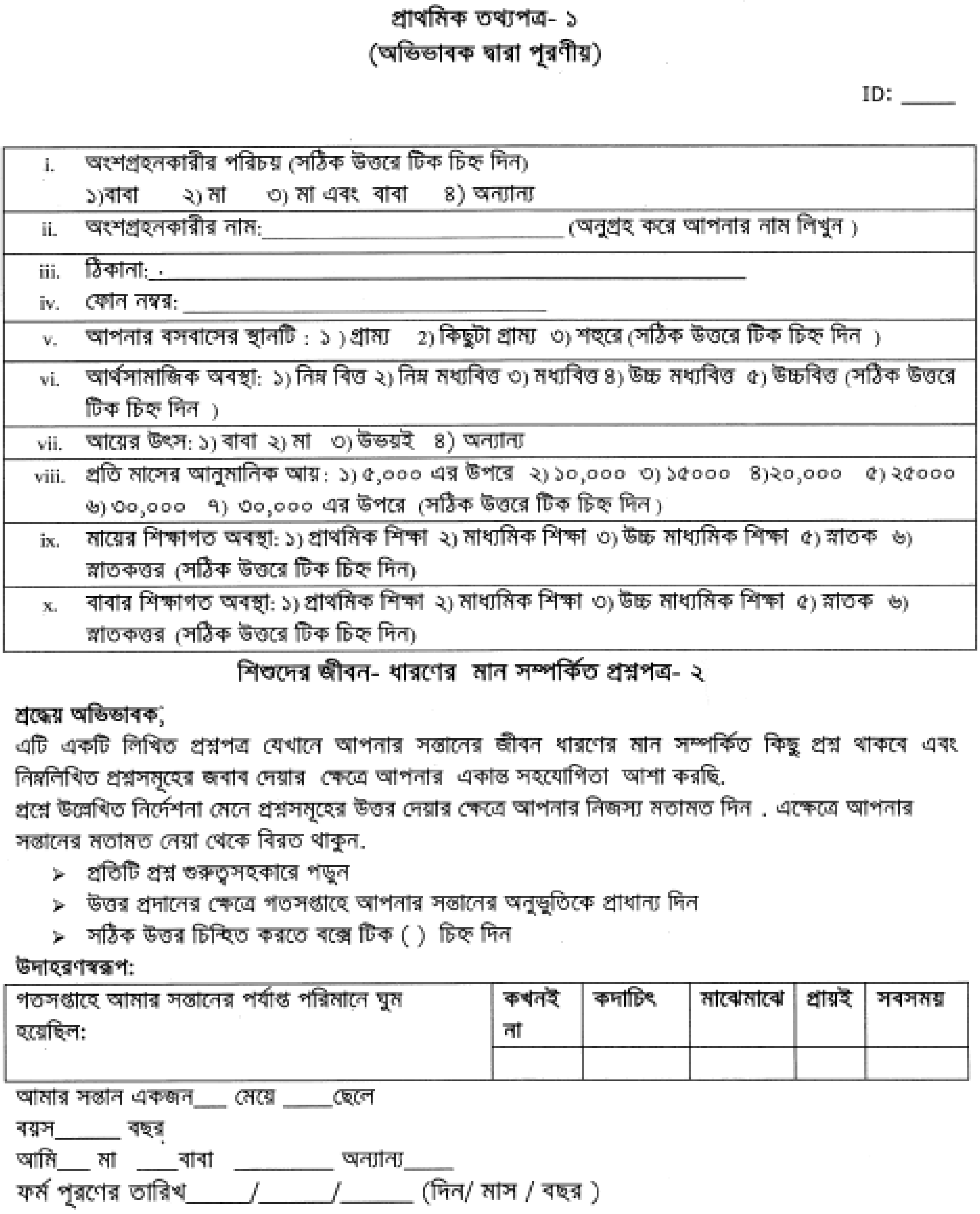
সাক্ষর______________________ তারিখ___________________

গবেষক

আমি গবেষনার বিষয়বস্তু অংশগ্রহনকারীদের কাছে সুক্ষভাবে ব্যাক্ষা করেছি এবং অংশগ্রহনকারী অংশগ্রহনের ইচ্ছা প্রকাশের ক্ষেত্রে তাদের নিজস্য মতামত দেয়ার সুযোগ পেয়েছে.

গবেষকের সাক্ষর ______________________ তারিখ ___________________

Appendix-4
Bengali Version of the Questionnaire



প্রাথমিক তথ্যপত্র- ১

(অভিভাবক দ্বারা পূরণীয়)

ID: _____

i.	অংশগ্রহনকারীর পরিচয় (সঠিক উত্তরে টিক চিহ্ন দিন) ১)বাবা ২) মা ৩) মা এবং বাবা ৪) অন্যান্য
ii.	অংশগ্রহনকারীর নাম:_____________________________ (অনুগ্রহ করে আপনার নাম লিখুন)
iii. iv.	ঠিকানা:____ ফোন নম্বর: ____________________________________
v.	আপনার বসবাসের স্থানটি : ১) গ্রাম্য 2) কিছুটা গ্রাম্য ৩) শহুরে (সঠিক উত্তরে টিক চিহ্ন দিন)
vi.	আর্থসামাজিক অবস্থা: ১) নিম্ন বিত্ত ২) নিম্ন মধ্যবিত্ত ৩) মধ্যবিত্ত ৪) উচ্চ মধ্যবিত্ত ৫) উচ্চবিত্ত (সঠিক উত্তরে টিক চিহ্ন দিন)
vii.	আয়ের উৎস: ১) বাবা ২) মা ৩) উভয়ই ৪) অন্যান্য
viii.	প্রতি মাসের আনুমানিক আয়: ১) ৫,০০০ এর উপরে ২) ১০,০০০ ৩) ১৫০০০ ৪)২০,০০০ ৫) ২৫০০০ ৬) ৩০,০০০ ৭) ৩০,০০০ এর উপরে (সঠিক উত্তরে টিক চিহ্ন দিন)
ix.	মায়ের শিক্ষাগত অবস্থা: ১) প্রাথমিক শিক্ষা ২) মাধ্যমিক শিক্ষা ৩) উচ্চ মাধ্যমিক শিক্ষা ৫) স্নাতক ৬) স্নাতকত্তর (সঠিক উত্তরে টিক চিহ্ন দিন)
x.	বাবার শিক্ষাগত অবস্থা: ১) প্রাথমিক শিক্ষা ২) মাধ্যমিক শিক্ষা ৩) উচ্চ মাধ্যমিক শিক্ষা ৫) স্নাতক ৬) স্নাতকত্তর (সঠিক উত্তরে টিক চিহ্ন দিন)

শিশুদের জীবন- ধারণের মান সম্পর্কিত প্রশ্নপত্র- ২

শ্রদ্ধেয় অভিভাবক,

এটি একটি লিখিত প্রশ্নপত্র যেখানে আপনার সন্তানের জীবন ধারণের মান সম্পর্কিত কিছু প্রশ্ন থাকবে এবং নিম্নলিখিত প্রশ্নসমূহের জবাব দেয়ার ক্ষেত্রে আপনার একান্ত সহযোগিতা আশা করছি.

প্রশ্নে উল্লেখিত নির্দেশনা মেনে প্রশ্নসমূহের উত্তর দেয়ার ক্ষেত্রে আপনার নিজস্ব মতামত দিন . এক্ষেত্রে আপনার সন্তানের মতামত নেয়া থেকে বিরত থাকুন.

- প্রতিটি প্রশ্ন গুরুত্বসহকারে পড়ুন
- উত্তর প্রদানের ক্ষেত্রে গতসপ্তাহে আপনার সন্তানের অনুভুতিকে প্রাধান্য দিন
- সঠিক উত্তর চিহ্নিত করতে বক্সে টিক ( ) চিহ্ন দিন

উদাহরণস্বরূপ:

গতসপ্তাহে আমার সন্তানের পর্যাপ্ত পরিমানে ঘুম হয়েছিল:	কখনই না	কদাচিৎ	মাঝেমাঝে	প্রায়ই	সবসময়

আমার সন্তান একজন___ মেয়ে ____ছেলে

বয়স______ বছর

আমি___ মা ____বাবা ________ অন্যান্য____

ফর্ম পূরণের তারিখ_____/______/______ (দিন/ মাস / বছর)

১) শারীরিক অবস্থা/ সুস্থতা

গতসপ্তাহে...	কখনই না	কদাচিৎ	মাঝেমাঝে	প্রায়ই	সবসময়
১) আমার সন্তান অসুস্থতা অনুভব করেছিল					
২) আমার সন্তানের মাথা ও পেটে বেথা ছিল					
৩) সে ক্লান্ত এবং অবসাদগ্রস্থ ছিল					
৪) সে নিজেকে সবল এবং শক্তিতে ভরপুর মনে করেছিল					

২) আবেগিক অবস্থা/ সুস্থতা

গতসপ্তাহে...	কখনই না	কদাচিৎ	মাঝেমাঝে	প্রায়ই	সবসময়
১) আমার সন্তান আনন্দে ছিল এবং অনেক হাসিখুশি ছিল					
২) সে কোনো কাজ করার ক্ষেত্রে খুব বেশি তৎপর ছিল না					
৩) সে নিঃসঙগ/ একা বোধ করেছিল					
৪) আমার সন্তান তার নিজের সম্পর্কে ভীত এবং অনিশ্চিত ছিলো					

৩) আত্মবিশ্বাস

গতসপ্তাহে...	কখনই না	কদাচিৎ	মাঝেমাঝে	প্রায়ই	সবসময়
১)আমার সন্তান নিজেকে নিয়ে গর্বিত ছিলো					
২) যে কোন কাজের সাফল্য তার আত্মবিশ্বাস কে অনেক বাড়িয়ে দিয়েছিল					
৩)আমার সন্তান নিজের প্রতি সন্তুষ্ট ছিলো					
৪)সে নতুন অনেক কিছু সম্পর্কে জানতে পেরেছিল					

৪) পরিবার

গতসপ্তাহে...	কখনই না	কদাচিৎ	মাঝেমাঝে	প্রায়ই	সবসময়
১) সে পিতামাতা/ অভিভাবক হিসেবে আমাদের সঙ্গ উপভোগ করেছিলো					
২) সে বাড়িতে ভালো সময় কাটিয়েছিলো					
৩) আমাদের ঝগড়া হয়েছিলো					
৪)সে অনুভব করছিলো যে আমি তাকে সবসময় নিয়ন্ত্রণ করার চেষ্টা করছি					

৫) সামাজিক সম্পর্ক/ যোগাযোগ

গতসপ্তাহে...	কখনই না	কদাচিৎ	মাঝেমাঝে	প্রায়ই	সবসময়
১) আমার সন্তান বিভিন্ন কাজ তার বন্ধুদের সাথে করেছিল					

বাড়ির বাইরে টয়লেট ব্যবহার করা এবং পরে পানি ব্যবহার করা	সাহায্যের প্রয়োজন হয় না	সহায়ক উপকরণ	পরিবেশ বা কাজের কাঠামোগত পরিবর্তন	সাহায্যের প্রয়োজন হয়
শরীরের উপরিভাগের পোশাক পরিধান এবং পরিত্যাগ করা (বোতাম এবং চেইন লাগানো, পরিধানের জন্য পোশাক পছন্দ করা সহ)				
শরীরের নিচের অংশের পোশাক পরিধান এবং পরিতাগ করা (বোতাম এবং চেইন লাগানো, পরিধানের জন্য পোশাক পছন্দ করা সহ)				
সহায়ক উপকরনের ক্ষেত্রে: তা পরা, খুলে রাখা এবং যত্ন করা (হুইল চেয়ার, hearing aid বা কানে শোনার যন্ত্র, চোখের লেন্স, চশমা, ঔষধ ইত্যাদি))				
ক্লিনিক, হাসপাতাল, পুনর্বাসন কেন্দ্র থেকে সেবা নেয়ার ক্ষেত্রে				

বক্স-৩: আপনার সন্তান দ্বারা নিচে উল্লেখিত প্রতিটি কাজ সম্পন্ন করার ক্ষেত্রে অভিভাবক হিসেবে আপনার সন্তুষ্টি নির্দেশ করুন:	**খুবই অসন্তুষ্ট**	**অসন্তুষ্ট**	**কিছুটা সন্তুষ্ট**	**সন্তুষ্ট**	**খুবই সন্তুষ্ট**
নিজস্য/ ব্যক্তিগত পরিচ্ছন্নতার কাজে অংশগ্রহন (হাত-মুখ ধোয়া, দাত ব্রাশ করা, চুল আচড়ানো, গোসল করা) আর ক্ষেত্রে:					
বাড়িতে টয়লেট ব্যবহার করা এবং পরে পানি ব্যবহার করার ক্ষেত্রে:					
বাড়ির বাইরে টয়লেট ব্যবহার করা এবং পরে পানি ব্যবহার করা					
শরীরের উপরিভাগের পোশাক পরিধান এবং পরিতাগ করা (বোতাম এবং চেইন লাগানো, পরিধানের জন্য পোশাক পছন্দ করা সহ)					
শরীরের নিচের অংশের পোশাক পরিধান এবং পরিতাগ করা (বোতাম এবং চেইন লাগানো, পরিধানের জন্য পোশাক পছন্দ করা সহ)					
সহায়ক উপকরনের ক্ষেত্রে: তা পরা, খুলে রাখা এবং যত্ন করা (হুইল চেয়ার, hearing aid বা কানে শোনার যন্ত্র, চোখের লেন্স, চশমা, ঔষধ ইত্যাদি)					
ক্লিনিক, হাসপাতাল, পুনর্বাসন কেন্দ্র থেকে সেবা নেয়ার ক্ষেত্রে					

প্রশ্নপত্র-৩

বক্স-১: নিচে উল্লেখিত প্রতিটি কাজের ক্ষেত্রে নির্দেশ করুন: আপনার সন্তান সচরাচর কিভাবে এই কাজটি সম্পন্ন করে।	(কাজ সম্পন্নের ধাপ : যেকোনো একটি নির্দেশ করুন)				
	কোন সমস্যা নেই	সমস্যা আছে	অন্য কাউকে করিয়ে দিতে হয়	সম্পন্ন করতে পারে না	প্রযোজ্য না/ প্রয়োজন হয় না
নিজস্য/ ব্যক্তিগত পরিচ্ছন্নতার কাজে অংশগ্রহন (হাত- মুখ ধোয়া, দাত ব্রাশ করা, চুল আচড়ানো, গোসল করা) করার ক্ষেত্রে:					
বাড়িতে টয়লেট ব্যবহার করা এবং পরে পানি ব্যবহার করার ক্ষেত্রে:					
বাড়ির বাইরে টয়লেট ব্যবহার করা এবং পরে পানি ব্যবহার করা					
শরীরের উপরিভাগের পোশাক পরিধান এবং পরিত্যাগ করা (বোতাম এবং চেইন লাগানো, পরিধানের জন্য পোশাক পছন্দ করা সহ)					
শরীরের নিচের অংশের পোশাক পরিধান এবং পরিতাগ করা (বোতাম এবং চেইন লাগানো, পরিধানের জন্য পোশাক পছন্দ করা সহ)					
সহায়ক উপকরন ব্যবহারের ক্ষেত্রে: তা পরা, খুলে রাখা এবং যত্ন করা (হুইল চেয়ার, hearing aid বা কানে শোনার যন্ত্র, চোখের লেন্স, চশমা, ঔষধ ইত্যাদি)					
ক্লিনিক, হাসপাতাল, পুনর্বাসন কেন্দ্র থেকে সেবা নেয়ার ক্ষেত্রে					

বিশেষ দ্রষ্টব্য: পরিবেশ বা কাজের কাঠামোগত পরিবর্তন বলতে রাম্প, প্রশস্ত দরজা, কাজের পরিবর্তন এবং কোন কাজ করতে অতিরিক্ত সময় নেয়াকে বোঝানো হয়েছে.
সহায়ক উপকরণ হলো হুইল চেয়ার, চশমা বা লেন্স, কানে শোনার যন্ত্র, ঔষধ ইত্যাদি।

বক্স-২: প্রতিটি কাজ শেষ করতে তার কি ধরনের সাহায্য দরকার হয়:	সহযোগিতার ধরন (এক বা একাধিক পরিক্ষনীয়)			
	সাহায্যের প্রয়োজন হয় না	সহায়ক উপকরণ	পরিবেশ বা কাজের কাঠামোগত পরিবর্তন	সাহায্যের প্রয়োজন হয়
নিজস্য/ ব্যক্তিগত পরিচ্ছন্নতার কাজে অংশগ্রহন (হাত- মুখ ধোয়া, দাত ব্রাশ করা, চুল আচড়ানো, গোসল করা) আর ক্ষেত্রে:				
বাড়িতে টয়লেট ব্যবহার করা এবং পরে পানি ব্যবহার করার ক্ষেত্রে:				

বাড়ির বাইরে টয়লেট ব্যবহার করা এবং পরে পানি ব্যবহার করা	**সাহায্যের প্রয়োজন হয় না**	**সহায়ক উপকরণ**	**পরিবেশ বা কাজের কাঠামোগত পরিবর্তন**	**সাহায্যের প্রয়োজন হয়**
শরীরের উপরিভাগের পোশাক পরিধান এবং পরিত্যাগ করা (বোতাম এবং চেইন লাগানো, পরিধানের জন্য পোশাক পছন্দ করা সহ)				
শরীরের নিচের অংশের পোশাক পরিধান এবং পরিতাগ করা (বোতাম এবং চেইন লাগানো, পরিধানের জন্য পোশাক পছন্দ করা সহ)				
সহায়ক উপকরনের ক্ষেত্রে: তা পরা, খুলে রাখা এবং যত্ন করা (হুইল চেয়ার, hearing aid বা কানে শোনার যন্ত্র, চোখের লেন্স, চশমা, ঔষধ ইত্যাদি))				
ক্লিনিক, হাসপাতাল, পুনর্বাসন কেন্দ্র থেকে সেবা নেয়ার ক্ষেত্রে				

বক্স-৩: আপনার সন্তান দ্বারা নিচে উল্লেখিত প্রতিটি কাজ সম্পন্ন করার ক্ষেত্রে অভিভাবক হিসেবে আপনার সন্তুষ্টি নির্দেশ করুন:	**খুবই অসন্তুষ্ট**	**অসন্তুষ্ট**	**কিছুটা সন্তুষ্ট**	**সন্তুষ্ট**	**খুবই সন্তুষ্ট**
নিজস্য/ বাক্তিগত পরিচ্ছন্নতার কাজে অংশগ্রহন (হাত-মুখ ধোয়া, দাত ব্রাশ করা, চুল আচড়ানো, গোসল করা) আর ক্ষেত্রে:					
বাড়িতে টয়লেট ব্যবহার করা এবং পরে পানি ব্যবহার করার ক্ষেত্রে:					
বাড়ির বাইরে টয়লেট ব্যবহার করা এবং পরে পানি ব্যবহার করা					
শরীরের উপরিভাগের পোশাক পরিধান এবং পরিতাগ করা (বোতাম এবং চেইন লাগানো, পরিধানের জন্য পোশাক পছন্দ করা সহ)					
শরীরের নিচের অংশের পোশাক পরিধান এবং পরিতাগ করা (বোতাম এবং চেইন লাগানো, পরিধানের জন্য পোশাক পছন্দ করা সহ)					
সহায়ক উপকরনের ক্ষেত্রে: তা পরা, খুলে রাখা এবং যত্ন করা (হুইল চেয়ার, hearing aid বা কানে শোনার যন্ত্র, চোখের লেন্স, চশমা, ঔষধ ইত্যাদি)					
ক্লিনিক, হাসপাতাল, পুনর্বাসন কেন্দ্র থেকে সেবা নেয়ার ক্ষেত্রে					

Appendix- 5: Information Sheet

I am Tahmida Akter, student of Bangladesh Health Professions Institute (BHPI) which is an academic institution of the Centre for the Rehabilitation of the Paralyzed (CRP), Savar, Dhaka. Currently I am pursuing B.Sc. in Occupational Therapy (4 years course) under the Medicine faculty of Dhaka University. In regard to the fulfillment of the course module it is obligatory to conduct a research in 4th year of the study. I would like to invite you to take part in the research study, titled “The influence of the participation of the self-care activities on the quality of life of children with cerebral palsy” which will be conducted by Tahmida Akter. The aim of the study is to find out the influence of the participation in the self-care activities on the quality of life of children with cerebral palsy.

Your participation in this study is voluntary. If you are not agree to participate at all you can withdraw from the study anytime you want, despite consenting to take part earlier. There will be no change of treatment of your child in regards to participation or not to be participated in this study. If you do not want to participate or withdraw from the study, you may do so at any time.

Your answer will be recorded in this questionnaire which will take approximately 40 minutes. You will not be paid for your participation. Participation in this study might not benefit your child directly. This study will not the cause of any risk or harm of you or your child. However, it is very important to know the influence of the participation of the self-care activities on the quality of life of children with cerebral palsy to improve the quality of life of children with CP.

Confidentiality of all records will be highly maintained. Gathered data will never be used in such a way that you or your child could be identified in any presentation or publication without your permission.

If you have any question now or later regarding the study, please feel free to ask the person stated below.

Tahmida Akter
B.Sc. in Occupational Therapy
4th year, Occupational Therapy Department,
Bangladesh Health Professions Institute (BHPI),
Centre for the Rehabilitation of the Paralyzed (CRP), Savar, Dhaka.

Appendix- 6: Consent Form

“I have read this information sheet and I am informed about the topic of the research. I have got opportunity to ask my query and discuss about the study with the researcher where I got satisfactory answer. I have informed about the risk and benefit of the research. I have understood that I am free to withdraw from the study at any time, without having to give a reason and without affecting present and future medical care of your children. I am informed that all answer of mine will remain highly confidential. For that reason I am agree to take part in this study”.

Do you agree with this statement? Ans.: 1) Yes 2) No

Participant’s signature___________________________ Date___________

Investigator

I have explained the study to the above participant precisely and he/she has indicated her willingness to take part in the study.

Investigator’s signature_____________________________Date_____________

Appendix-7: Questionnaire- 1

English Version of the Questionnaire

ID: ___ ___ ___ ___ ___

Quality of Life Questionnaire for Children

8 – 16 years
Parents' Questionnaire KINDL^{R}

Dear Parent,

We really appreciate your taking the time to complete this questionnaire about your child's well-being and health-related quality of life.

Since it is a matter of **your** own assessment of your child's well-being, please complete the questionnaire yourself according to the instructions, i.e. without asking your child.

- ⇨ Read each question carefully.
- ⇨ Think about how your child has been feeling during the past week.
- ⇨ Put a cross in the box corresponding to the answer **in each line** that fits your child best.

For example:

During the past week ...	never	seldom	some-times	often	all the time
. ...my child has slept well	☐	☐	☐	☒	☐

My Child is a: ☐ Girl ☐ Boy

Age: _____ Years

You are: ☐ Mother ☐ Father ☐ Other ________________?

Date of fill out: ___ / ___ / ___ (day / month / year)

1. Physical Well-being

During the past week ...	never	seldom	some-times	often	all the time
1. ... my child felt ill	☐	☐	☐	☐	☐
2. ... my child had a headache or tummy-ache	☐	☐	☐	☐	☐
3. ... my child was tired and worn-out	☐	☐	☐	☐	☐
4. ... my child felt strong and full of energy	☐	☐	☐	☐	☐

2. Emotional Well-being

During the past week ...	never	seldom	some-times	often	all the time
1. ... my child had fun and laughed a lot	☐	☐	☐	☐	☐
2. ... my child didn't feel much like doing anything	☐	☐	☐	☐	☐
3. ... my child felt alone	☐	☐	☐	☐	☐
4. ... my child felt scared or unsure of him-/ herself	☐	☐	☐	☐	☐

3. Self-esteem

During the past week ...	never	seldom	some-times	often	all the time
1. ... my child was proud of him-/herself	☐	☐	☐	☐	☐
2. ... my child felt on top of the world	☐	☐	☐	☐	☐
3. ... my child felt pleased with him-/ herself	☐	☐	☐	☐	☐
4. ... my child had lots of good ideas	☐	☐	☐	☐	☐

4. Family

During the past week ...	never	seldom	some-times	often	all the time
1. ... my child got on well with us as parents	☐	☐	☐	☐	☐
2. ... my child felt fine at home	☐	☐	☐	☐	☐
3. ... we quarrelled at home	☐	☐	☐	☐	☐
4. ... my child felt that I was bossing him/ her around	☐	☐	☐	☐	☐

5. Social Contacts

During the past week ...	never	seldom	some-times	often	all the time
1. ... my child did things together with friends	☐	☐	☐	☐	☐
2. ... my child was liked by other kids	☐	☐	☐	☐	☐
3. ... my child got along well with his/ her friends	☐	☐	☐	☐	☐
4. ... my child felt different from other children	☐	☐	☐	☐	☐

6. School

During the last week in which my child was at school ...	never	seldom	some-times	often	all the time
1. ... my child easily coped with schoolwork	☐	☐	☐	☐	☐
2. ... my child enjoyed the school lessons	☐	☐	☐	☐	☐
3. ... my child worried about his/her future	☐	☐	☐	☐	☐
4. ... my child was afraid of bad marks or grades	☐	☐	☐	☐	☐

7. Is your child staying in hospital just now or does it have a long-term illness?

☐ **Yes**
please answer the
following 6 questions

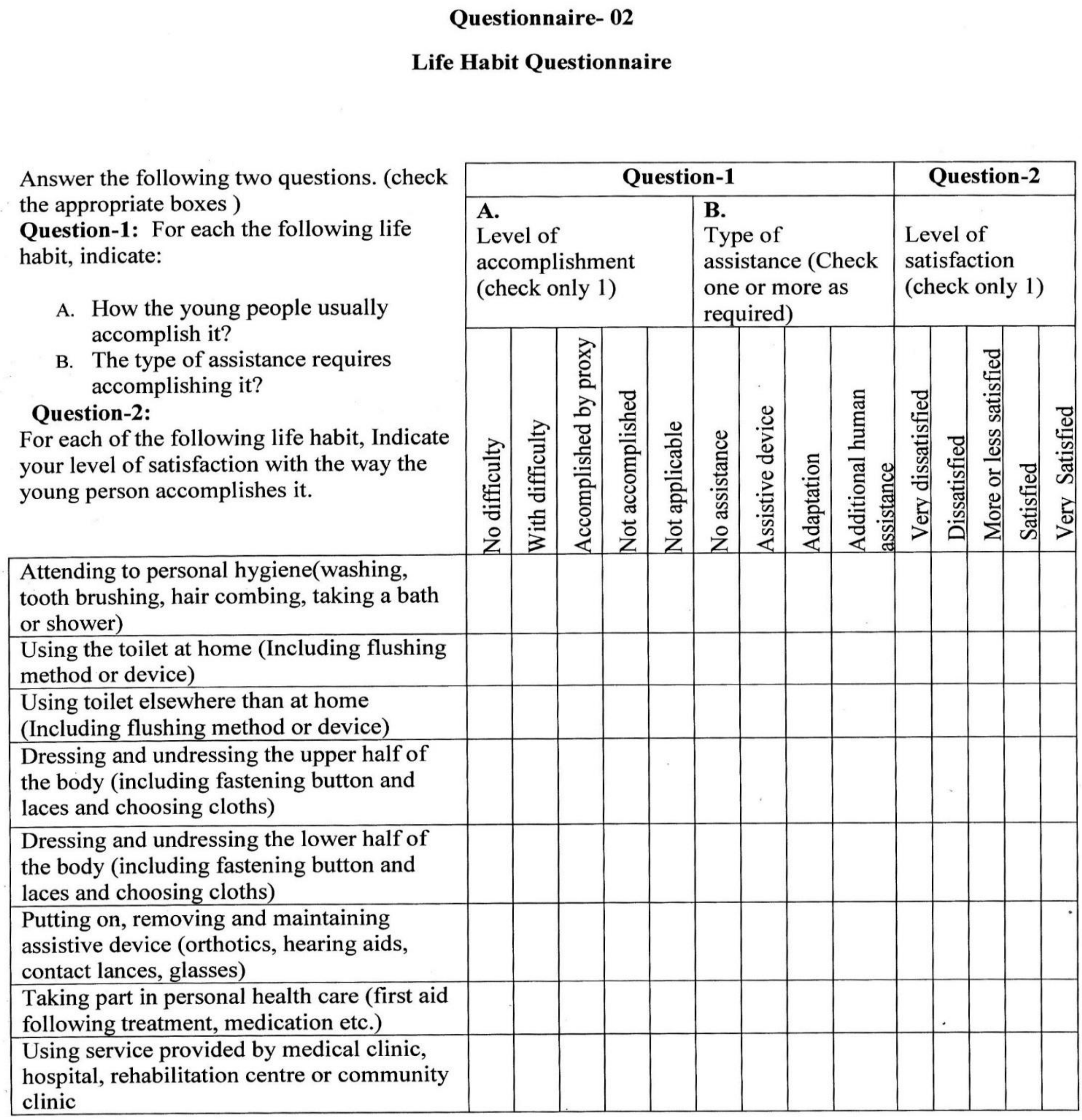
☐ **No**
the questionnaire is done

During the past week ...	never	seldom	some-times	often	all the time
1. ... my child was afraid that the illness might get worse	☐	☐	☐	☐	☐
2. ... my child was sad because of the illness	☐	☐	☐	☐	☐
3. ... my child was able to cope well with his/ her illness	☐	☐	☐	☐	☐
4. ... we treated our child as though he/ she were younger, because of the illness	☐	☐	☐	☐	☐
5. ... my child avoided others to notice his/ her illness	☐	☐	☐	☐	☐
6. ... my child missed something at school because of his/her illness	☐	☐	☐	☐	☐

Thank you for your co-operation!

Appendix-8: English Version of Questionnaire

Life Habit Questionnaire for Measuring the Participation of the self- care activities



Questionnaire- 02

Life Habit Questionnaire

Answer the following two questions. (check the appropriate boxes)

Question-1: For each the following life habit, indicate:

A. How the young people usually accomplish it?
B. The type of assistance requires accomplishing it?

Question-2:
For each of the following life habit, Indicate your level of satisfaction with the way the young person accomplishes it.

	Question-1									**Question-2**				
	A. Level of accomplishment (check only 1)					**B.** Type of assistance (Check one or more as required)				Level of satisfaction (check only 1)				
	No difficulty	With difficulty	Accomplished by proxy	Not accomplished	Not applicable	No assistance	Assistive device	Adaptation	Additional human assistance	Very dissatisfied	Dissatisfied	More or less satisfied	Satisfied	Very Satisfied
Attending to personal hygiene(washing, tooth brushing, hair combing, taking a bath or shower)														
Using the toilet at home (Including flushing method or device)														
Using toilet elsewhere than at home (Including flushing method or device)														
Dressing and undressing the upper half of the body (including fastening button and laces and choosing cloths)														
Dressing and undressing the lower half of the body (including fastening button and laces and choosing cloths)														
Putting on, removing and maintaining assistive device (orthotics, hearing aids, contact lances, glasses)														
Taking part in personal health care (first aid following treatment, medication etc.)														
Using service provided by medical clinic, hospital, rehabilitation centre or community clinic														