PARENTS VIEW ON BARRIERS OF PARTICIPATING IN DAILY PHYSICAL ACTIVITIES OF THE CHILDREN WITH CEREBRAL PALSY

Rukaiya Islam Ela

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

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BHPI, CRP, Savar, Dhaka



Bangladesh Health Professions Institute (BHPI)

Department of Physiotherapy

CRP, Savar, Dhaka-1343

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

"PARENTS VIEW ON BARRIERS OF PARTICIPATING IN DAILY PHYSICAL ACTIVITIES OF THE CHILDREN WITH CEREBRAL PALSY"

Submitted by **Rukaiya Islam Ela**, for the partial fulfillment of the requirement for the degree of Bachelor of Science in Physiotherapy (B.Sc. PT).

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Muhammad Millat Hossain Assistant Professor Department of Rehabilitation Science BHPI, CRP, Savar, Dhaka Supervisor

Professor Md. Obaidul Haque Vice Principal BHPI, CRP, Savar, Dhaka

Mohammad Anwar Hossain Associate Professor, Physiotherapy, BHPI Head of the Department of Physiotherapy CRP, Savar, Dhaka

E. Rolman Ehsanur Rahman Associate Professor & MPT Coordinator Department of Physiotherapy BHPI, CRP, Savar, Dhaka

Md. Shofiqul Islam Associate Professor & Head Department of Physiotherapy BHPI, CRP, Savar, Dhaka

DECLARATION

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

Signature: Rukaiya Islam Ela

Date: 15/11/2021

Rukaiya Islam Ela Bachelor of Science in Physiotherapy (B.Sc. PT) DU Roll no: 936 Reg.no: 3645 Session: 2015-2016 BHPI, CRP, Savar, Dhaka-1343

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Acronyms

&	And
ADL	Activities of Daily Living
BHPI	Bangladesh Health Professions Institute
BMRC	Bangladesh Medical Research Council
СР	Cerebral Palsy
CRP	Centre for Rehabilitation of the Paralysed
ICF	International Classifications of Functioning, Disability and Health
IRB	Institutional Review Board
NGO	Non-governmental organization
PA	Physical Activity
РТ	Physical Therapy
QoL	Quality of Life
SCPE	Society for the Study of CP in Europe
WHO	World Health Organization

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Abstract

Purpose: The purpose of the study was to identify the perception of parents on barriers of participating in daily physical activity of their children with cerebral palsy. *Objectives:* The objectives were to find out the barriers that are faced during participating daily physical activity. *Methodology:* A qualitative study design was used to conduct the study where ten cerebral palsy children parents selected by purposive sampling method. The data were collected by using a semi structured open ended questionnaire form and were analyzed through content analysis. *Results:* The parents interviewed reported that parent's perception of barriers their child with cerebral palsy faced during daily activity. Lacking of the knowledge about cerebral palsy of their parents, couldn't do self-care activity, delayed developmental millstone, faced the prejudice and social stigma from family members, relatives, neighbors and other community people for their condition and their psychological behavior were main barriers. So, identification of these barriers will help to indicate on designing the overcoming strategy of those barriers.

Key words: Cerebral palsy, Physical activity, Perception, Barrier.

CHAPTER-I

1.1 Background

Cerebral palsy is one of the common neuro developmental disorders of children that associated with motor impairment & disability over the life span. This disorder results from the injury and defect of the developing brain that causes the abnormal formation of nervous system which causes continuous abnormality of limbs strength, control or both (Aisen et al., 2011).

Cerebral Palsy (CP) defines a bunch of conditions, arising from associate degree injury to the developing brain and happens in two children per a thousand live births. Additionally to the disturbances of movement and posture as well as fitfulness, muscle weakness and reduced coordination, common impairments of children with CP embody disturbances of sensation, perception, cognition, communication, behavior, epilepsy, and secondary system issues. Reduced activity levels and participation restrictions because of these impairments might cause a reduced quality of life (QoL), compared to their usually developing peers (Carlon et al., 2010).

These injured developing brain result in impairments in physical soundness and physical activity levels in persons with CP. Reduced physical soundness and physical activity will act to cause a cycle of de-conditioning low physical soundness which lead to end in high physical strain throughout activities of daily living (ADL's), probably resulting in a discount in activity and consequently, any decreasing physical soundness. Moreover, physical soundness is understood to contribute to health and quality of lifetime of persons with chronic conditions (Nooijen et al., 2014).

Participation in daily living activity has important health and social benefits for young people with cerebral palsy (Fowler et al., 2007). Young people with cerebral palsy do not take part in daily activities to the same extent as their typically developing peers, or to the levels recommended by national guidelines (Carlon et al., 2013) This, in part, may be because they have difficulty with movement and posture.

However, many other barriers, both internal and external, also contribute to the low levels of physical activity (PA) and high levels of sedentary time that are typical of young people with cerebral palsy (Carlon et al., 2013). A number of studies have detailed the barriers to and facilitators of physical activity participation for young people with disabilities (including cerebral palsy) in the community (Shields et al., 2012) however, little is known about the barriers to and facilitators of participation in physical activity at school. While one study (Conchar et al., 2017) explored the experiences of daily activity of students who attended a special school and gave great insight into the views of the students, the views of parents, teachers, and therapists were not included.

The first responses of guardians after a incapacity diagnosis of their children, they are gotten to be sense of bad form, hatred against destiny, faulting each other and gotten to be disillusioned (Hung et al., 2010).

Parents who have such children may suffer from different conditions such as depression, anxiety, anger, fear, shame and desire to die. But children's common enhancement specifically related to caregivers commitment and concern (Marx et al., 2011). For a child, care-giving plays an critical part but giving the care for a child with long-term useful restrictions is totally distinctive and it has a negative effect on guardians particularly mother in terms of requests on physical wellbeing, disturbed rest, trouble in keeping up social connections, weight on conjugal connections, economical burden may increments day by day. Parents of children with CP have lower quality of life and high level of sadness, anxiety (Sajedi et al., 2010). These parents faced many barriers for their child in daily activity work.

The child will not make this behavior change in isolation and while it is important to give them choice and control in selection of activities, the role of the family and the child's clinicians is also critical to achieving successful long-term behavior change (Brunton, 2017). Frameworks such as the Trans theoretical Model of Behavior Change have been suggested as a means to guide young people and their family towards an enjoyable and sustainable active lifestyle (Verschuren et al., 2013). Barriers to physical activity participation for young people with a physical disability from the young person's perspective have been well described, particularly for those with CP. Some of these are consistent with barriers described by typically developing young people (e.g., disinterest, lack of time, intention, and older age); others are more specific to people with a physical disability and include: lack of accessible programs/equipment, bodily limitations or pain/discomfort and fatigue, dependency on others, lack of acceptance by others or people's misconception of the individual's physical condition or ability, and a feeling of "not being good enough" (Bloemen et al., 2015)

In Australia, CP happening in roughly 2 to 2.5 per 1000 live births which is the primary cause of physical incapacity in children. There has been total intrigued in the quality of life of children with CP in later a long time. In USA, caregivers of children with CP may be beneath more physical, mental, and money related burdens compared with those who give care for children who create in a normal way since their duties are more prominent. In expansion to giving coordinate every day care and back, caregivers of children with CP contribute time and exertion in helping with intercessions such as physical, word related, and discourse treatment. In this way recognition of caregivers' or guardians almost their child's needs and endeavors related to the everyday care of their children likely to have considerable effect on the choice and victory of the child's rehabilitative administration. In UK, one in five children with CP (20.2%) was found. They had a separate mental shortage and were incapable to walk. Among those babies birth weight is less than 1500g, the rate of CP was more than 70 times higher compared with those weight is 2500g or more at birth, the rate of CP rose during the 1970s, but remained steady during the late1980s (Johnson et al., 2002).

A large number of children with cerebral palsy need better physiotherapy treatment for better survival in the community. Cerebral palsy cannot be cured but treatment can improve child capability. The earlier treatment can be made more improvement of the child with cerebral palsy. In realizing this truth some NGO"s such as CRP (Centre for Rehabilitation of the Paralysed), Bangladesh Protibondhi Foundation, BRAC Inclusive Education Programme, Assistant for Blind Children, Impact Foundation Bangladesh, Shishu Bikash, Shishu pally and Shishu hospital, Institute of child and mother health and also some other organization have taken step to provide physiotherapy service (Biswas, 2017). Among these NGO's only CRP have an individual pediatric unit for the children with cerebral palsy which provide Physiotherapy, Occupation therapy and Speech and language therapy service. In Bangladesh there is only one non-government organization CRP has realized the importance of conducting a rehabilitation program for these children through can improve their lifestyle and functional independency. Subsequently, the premier point of finding barriers and taking therapy is to improve cerebral child condition.

Physical activity has numerous short and long-term health benefits, and because of these benefits, children with CP should be encouraged to engage in regular physical activity. However, activity programming must take into account potential barriers and modifications required based on an individual's unique abilities (Riner & Sellhorst 2013). Children and adolescents with CP engage in less physical activity than typically developing children, resulting in decreased aerobic and anaerobic capacity as well as poor health-related fitness. As a result, the goal of this study was to look at barriers to physical exercise in children with CP from both the child's and parent's perspectives, and to elicit detailed responses.

1.2 Rationale

Cerebral palsy is a common condition, mostly seen in developing country. Day by day there is increasing the number of cerebral palsy patient, in different areas. As Bangladesh is a developing country and trying to develop health care system so it is important to know the study will create and overview about barriers of their daily living activity on perception of those cerebral palsy parents.

As the physiotherapy profession is newly introduced in Bangladesh, many people are not aware of its purpose. But it is an important part of health care to prevent diseases as well as to improve or maximize independence in people with disabilities. As a child with cerebral palsy they face many barriers. If these barriers are not focused, awareness about child's problem cannot be raised. So, to improve the quality of life, it is important to focus on the patients barriers which they face. This study is about the parents overall perception on barriers of daily living activity of cerebral palsy child. It helps to know the obstacle of daily physical activity (PA) on the perception of parents about their cerebral palsy child. The researcher is interested to know the barriers to activity of daily living of the community living spinal cord injury people. Through this study enhances the knowledge about barriers of activity of daily living of spinal cord injured people in community and its nature. If people from all corner of the Bangladesh are aware about the barriers then it can help to minimize the barriers. The researcher is interested to know the barriers to activity of participating daily living of cerebral palsy children. Through this study enhances the knowledge about barriers of activity of daily living of cerebral palsy child in community and its nature. If people from all corner of the Bangladesh are aware about the barriers then it can help to minimize the barriers.

1.3 Research question

What are the parent's views on barriers of participating in daily physical activities of children with cerebral palsy?

1.4 Objectives

1.4.1 General objective

To determine the barrier of daily physical activity of children with cerebral palsy on their parent's view.

1.4.2 Specific objectives

- I. To identify the perception of parents on the barriers of physical activity
- II. To identify the perception of parents on barriers of self-care activities
- III. To find out the opinion of parents on barriers of getting around activities
- IV. To find out the perception of parents on barriers of communicate with family, relative's friend and others community people
- V. To find out the opinion of parents on barriers in house-hold activities
- VI. To find out the perception of parents on barriers to children with playful activities
- VII. To identify the obstructive psychological behavior of their children.

1.5 Operational definition

Cerebral palsy

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

Physical health

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

Physical activity (PA)

WHO defines physical activity as any bodily movement produced by skeletal muscles that requires energy expenditure.

Activities of daily living (ADL)

Activities of daily living (ADL) are routine activities that people tend do every day without needing assistance. There are six basic ADLs: eating, bathing, dressing, toileting, transferring (walking) and continence.

Barriers

An obstacles faced by the participations in their own community as well as their everyday tasks.

CHAPTER-II

LITERATURE REVIEW

Cerebral palsy is one of the most well-known forms of neurodevelopmental motor impairment in children. The term "spastic paralysis" refers to a loss of mobility in the brain (Alvarez, 2013). The word 'cerebral' refers to the brain, whereas 'palsy' refers to a developmental or weight condition. If someone has cerebral paralysis, it means that due to damage to the brain (cerebral), he or she is unable to use a few of the body's muscles in a normal manner. CP is a condition that affects the body's event and position.

The condition requires medical, educational, social, and rehabilitative resources throughout the lifespan (Hussain et al., 2012). Throughout one's life, the illness need medical, educational, social, and rehabilitative resources (Hussain et al., 2012). According to the American Academy of Pediatrics, cerebral palsy (CP) is a collection of permanent mobility and postural problems that cause activity restrictions and are caused by nonprogressive disruptions in the developing fetus or infant brain. Cerebral palsy has no known cause; nevertheless, various risk factors can contribute to the development of CP during the prenatal, natal, or postnatal period (Tatla et al., 2013). 70 to 80 percent of cerebral palsy cases are acquired prenatally for unknown reasons, while delivery problems, such as hypoxia, are thought to account for roughly 6% of congenital cerebral palsy patients, on the other hand neonatal risk factors for cerebral palsy include first cousin marriage birth after fewer than 32 weeks gestation, birth weight of less than 5 lb with intrauterine growth retardation, intracranial hemorrhage and trauma and about 10 to 20% patients (Chen et al., 2013), Preeclampsia affects 3-5% of pregnant women and is characterized by maternal hypertension and proteinuria occurring after 20 weeks of gestation (Melheim et al., 2013).

The pathological changes begin when specific causes produce brain injury, resulting in a loss of neuronal connection and transmission. Prolonged labor, sudden birth, birth asphyxia, infant did not cry immediately after birth, or delivery by forceps are all factors that contribute to cerebral palsy (Bangash et al., 2014). Toxic, infectious meningitis, encephalitis, and traumatic reasons such as drowning are all postnatal causes.

There's a link between coagulopathies that cause cerebral infarction and CP, especially hemiplegic CP. Postnatal episodes occur for 12–21% of all CP cases. However, the causes of CP are unknown in a vast majority of individuals (Kuak et al., 2014).

According to the Society for the Study of CP in Europe (SCPE), cerebral palsy is a group of long-term and non-progressive developmental and poses abnormalities caused by a central nervous system injury, impairment, or rupture that occurs early in infancy (Elkamil et al., 2011). Cerebral paralysis is a collection of long-term developmental or postural abnormalities induced by early brain injury. Despite the fact that a few factors such as preterm birth and low birth weight for development are linked to an increased risk of cerebral palsy, the causes of cerebral palsy remain mostly unknown. Pre-eclampsia influences 3-5% of pregnant ladies and is characterized by maternal hypertension and proteinuria happening after 20 weeks of incubation. Genuine signs may actuate iatrogenic preterm conveyance and preeclampsia contributes considerably to rashness, perinatal dismalness, and mortality. Early-onset pre-eclampsia is frequently associated with severe placental abnormalities, which can affect fetal blood flow, limiting fetal development, causing continuous hypoxia, and possibly brain damage.

As a result, it's possible that pre-eclampsia is a risk factor for cerebral paralysis (Melheim et al., 2013). Cousin marriage is one of the capable happening for cerebral palsy. Since cousins have one or both grandparents in common and on the off chance that either of the two grandparents, maternal or fatherly carries an imperfect recessive quality, Any child born to such consanguineous relational unions has a good possibility of becoming homozygous (Islam & Ahmed, 2009). When newborns are delivered at extremely low gestational ages, the risk of white matter damage and subsequent motor, cognitive, and behavioral impairments is increased. Preterm delivery can impair the developing brain due to low gestational age and white matter damage in the brain. Pregnancy disorders are also a risk factor for damaging the developing brain.

Cranial ultrasound injuries were showed that moreover causes CP analyzed afterward (McElrath et al., 2009). Cerebral palsy is the most prevalent physical disability in children and is a long-term disorder. Children with cerebral palsy are poorly understood in maturity, yet they frequently survive. Cerebral palsy is the most prevalent childhood chronic motor disability, affecting approximately 2 to 2.5 newborn children per 1,000 live births. Increased survival rates for premature newborns have increased the risk of brain wounds, which could lead to CP. CP has a huge financial impact on impacted

children and their families, in addition to the numerous health, social, and mental challenges that they face (Faria et al., 2011). In created nations, worldwide appraisals propose that CP influences between 1.2 and 3.0 per 1000 children (Hustad et al., 2011). In the Norwegian provinces there were 494 children with CP born between 1st January 1996 and 31st December 2003, comparing to a predominance of 2.65 per 1000 live births (Elkamil et al., 2011). The particular preponderance of CP in Associated States is debatable because to a lack of consistent statistics on population follow-up. A larger percentage of births are for term and late preterm newborn children. The United States estimated a prevalence of 3.6 cases per 1000 children at eight years of age where a population consider was appeared, based on data from three locations, however the study did not distinguish between children with and without a history of prematurity (Miller, 2013). In another study, it was discovered that CP may affect up to 3.6 per 1000 children in the United States (Hustad et al., 2011)

Physical exercise should be encouraged and maintained in children and adolescents (Boreham et al., 2001). Physical activity can help children with physical disabilities enhance their functional independence, emotional and social well-being, integration, and life satisfaction (Heath et al., 1997). Physical activity levels among children and youth with physical limitations have been increased via efforts (Murphy & Carbone, 2008). Changing this behavior necessitates consideration of contextual elements, such as school, community, and family engagement (van Sluijs et al., 2007).

Parental factors, family lifestyle, and the home environment are believed to influence the extent to which children and adolescents engage in physical activity (Trost et al., 2003) concluded that parental support is an important correlate of youth physical activity. It has been suggested that attempts to increase children's physical activity should target the whole family (Gortmaker et at., 1999). It is important to consider parents' attitudes toward their child's involvement, their goals for the child, and their perspectives on the child's activity potential. However, research on the values and preferences of families with children with disabilities is lacking. One study suggested that parents of children with cerebral palsy (CP) value opportunities for physical activity (Wiart et al., 2010).

Parents of disabled children have had to deal with a variety of mental health difficulties (Dehnavi et al., 2011). Guardians must monitor their child's challenging conduct, physical limitations, failure to complete daily living skills, sleep issues, and eating upsetting influences, all of which take a lot of time and require a lot of effort from parents. Furthermore, moms in Canada have a higher level of stress than fathers (Ogston-Nobile, 2014). Mothers are heavily involved in child rearing compared to fathers, which could be the cause of increased stress on mothers.

Several researches have looked into the underlying causes that are linked to reduced physical activity in children with cerebral palsy in the previous decade. Physical activity has been linked to motor capacity (i.e., Gross Motor Functional Classification System level); young people with CP with higher functional levels were consistently more active; however, even at higher functional levels of the Gross Motor Functional Classification System, most youth with CP do not meet minimum physical activity recommendations (Mitchell et al., 2016). While intervention trials in children and teens with CP show promise, there is limited evidence of successful therapies. Rurality is an underappreciated factor of physical activity in children with cerebral palsy. There is evidence that adults, particularly young ones, who live in rural areas are less happy.

On the contrary, because mothers are not sufficiently aware of the cause of their children's impairment, they vehemently blame themselves for their children's disability (Elfert, 2014).

Many parents described experiencing frequent bouts of rage, guilt, despair, and worry. They have a sense of helplessness. They are discovered to have a limited ability to deal by preserving their social system, self-esteem, and psychological and physical stability. Parents must maintain a high degree of responsibility and spend a significant amount of time with their special child, which causes them to be constantly stressed, which has a negative impact on their physical health.

Young individuals who engage in physical activity are happier and have more possibilities to improve their motor and social abilities (Reedman et al., 2007) Furthermore, habitual physical activity behavior established in childhood can be carried over into adulthood and contribute to a favorable risk profile for morbidity later in life (cited 2010 Sep 19). Children and young people aged 5 to 18 years should engage in moderate to intense physical exercise, according to Australian and international guidelines.

Activities for at least 60 min a day (cited 2017 Aug 31). In Australia, statistics show that only 60% of 5–17 year olds are fulfilling the physical activity recommendations (Verschuren, et al., 2016). A physically active lifestyle may confer even greater benefits for young people with disability, playing an important role in their health, participation, and social and emotional wellbeing (Maher et al., 2007). Despite this, young people with a disability generally participate in less physical activity than their able-bodied peers and it is critical to identify interventions that create meaningful long-term change in child and family physical activity behaviors.

Head injuries in babies a significant cause of cerebral palsy in the early months of life (American pregnancy association, 2017). Cerebral palsy has a variety of problems ranging from cognitive impairment, blindness, and hearing loss to short-term memory loss, language delays, learning challenges, and behavioral disorders (My Child, 2017). Cerebral palsy is a condition that can range from moderate to severe. With the right therapy, children with moderate cerebral palsy can live a near-normal life. Severe symptoms in children necessitate lifetime treatment. The child may or may not be able to walk, talk, or take care of himself. The child's potential can be maximized with proper care and treatment (Livestrong.com, 2017).

The child's prognosis is determined by the extent of brain injury. Although Cerebral Palsy cannot be healed, persons with the condition can live near-normal lives if their neurological issues are appropriately controlled (Right diagnosis, 2017). Contractures and deformities are caused by increased muscular tone. Due to the effects of gravity, muscles appear flabby, mushy, lack springiness, etc. in cases of poor muscular tone, such as drooping shoulders (Xinzhi, 2007). The improvement of CP children is hampered by abnormal muscle tone. Normal tone, hypertonia, hypotonia, and dystonia are the four different forms of muscle tone. Normal tone refers to joint movement that is free of any sudden rise or reduction in resistance. Hypertonia is a term that describes a greater

resistance to passive motion, which can be dependent or independent of motion direction. Hypotonia is a condition in which the body's resistance to passive motion is diminished, causing floppiness. Dystonia is a disorder in which muscle tone alternates between high and low (Xinzhi, 2007).

Barriers to physical activity participation for young people with a physical disability from the young person's perspective have been well described, particularly for those with CP. Some of these are consistent with barriers described by typically developing young people (e.g., disinterest, lack of time, intention, and older age); others are more specific to people with a physical disability and include: lack of accessible programs/equipment, bodily limitations or pain/discomfort and fatigue, dependency on others, lack of acceptance by others or people's misconception of the individual's physical condition or ability, and a feeling of "not being good enough" (Shimmell et al., 2013).

The first and most important treatment option for Cerebral palsy is Physical therapy which usually begins at early age and is geared toward improving independent motor function. The types of physical therapies used for children depend on their specific movement problems and symptoms that coincide with cerebral palsy. Physical therapy can improve Strength, Mobility, Posture, Balance, and Flexibility. Before giving physiotherapy intervention Physiotherapist make assessment to identify child's motor capabilities and determine the most appropriate measure for therapy based on the child's needs (CP Guide, 2017). Physical Therapy (PT) is a general name used to define treatment systems geared at treating muscles, nerves, joints, and bones with exercise, electrical stimulation, hydrotherapy, and the use of massage, heat, cold, and electrical devices. The treatment also consists of exercising specific parts of the body such as the legs, arms, hands or neck, in an effort to strengthen, regain range of motion, relearn movement and/or rehabilitate the musculoskeletal system to improve function (Xinzhi, 2007).

Physical therapy (PT) performs a major role in the management of cerebral palsy; it focuses on function, movement, and favorable use of the child's capability. Physiotherapist use physical approaches to improve & restore physical, psychological & social well-being. For feeding, bathing, dressing and other activities at home

physiotherapist also teach parents how to handle their children as well as advice on mobility device also (Anttila et al., 2008) Treating children with cerebral palsy necessitates a long-term process including a multidisciplinary team that focuses on all developmental elements of the kid while arranging interventions based on the primary needs of both the child and their family. Adulthood's proper functioning is the long-term goal (Scholtes et al., 2012).

According to current information, caring for a child with CP has numerous obstacles due to the nature of the impairment, which may be exacerbated by living in both a rural and an urban setting. Complex neurological and musculoskeletal deficits are common in children with cerebral palsy, and kids with CP confront specific hurdles to physical activity (Shimmell et al., 2013). Children with CP who live in remote locations may have delayed cognitive and motor development due to a lack of access to services. Rural youth with CP are less likely than urban youth to have adequate insurance, and the condition is more likely to have a negative impact on family employment (Schaible et al., 2018).

In an investigation of environmental barriers to recreational, community, and school participation, one of the only studies to compare physical activity levels between urban and rural kids with physical disabilities found no difference (Law et al., 2007). However, socioeconomic status was a major predictor of difficulties, which may have skewed the results because rural households are likely to be poorer. It's obvious that living in a rural area can make it more difficult for children with CP to engage in physical activity and daily activities. Children with CP should have their environmental barriers to involvement recognized (Welsh et al., 2006). By incorporating both qualitative and quantitative methodologies, previous research has been successful in elucidating personal and environmental barriers to physical exercise for children with CP.

The International Classification of Functioning, Disability and Health (ICF) model (World Health Organization, Geneva, 1999) provides a framework for a multidisciplinary, need-based team approach. The Rehabilitation Activities Profile for Children (Blair and Hatala, 1992) was created using this paradigm (Roelofsen et al.,

2001). Individuals with Cerebral Palsy are concerned about their body's strength and stability; the more stable a body is, the better a person can ambulate and execute jobs of all sizes.

Orthotic devices, which are worn on the body, aid to increase stability, strength, comfort, and independence (My Child, 2017)

Two-thirds of children with Cerebral Palsy are able to walk and ambulate, according to estimates. However, due of the nature of Cerebral Palsy and its impact on muscles, joints, and motion patterns, developing a meaningful gait might be difficult. When used correctly, an orthotic device can assist children in establishing appropriate joint and muscle motion patterns (My Child, 2017).

The role of parents changes when a child is born into a family. Parents anticipate the birth of their child with bated breath. Every parent hopes for a healthy baby who will bring them joy and calm. When a kid is born with a physical or developmental handicap, however, the situation becomes more complicated. It has a significant impact on parents' lives after having a kid with a disability. Cerebral palsy is a sort of severe developmental issue that is distinct from other children's illnesses. Parents' lives, especially mothers', become more stressful after having a child with cerebral palsy. After having a child with cerebral palsy, they encountered various difficulties. Furthermore, society and community members are under-aware of the disease, which is a cause for concern these days.

Cerebral palsy children require extra support and attention from their families. However, a child's behavior and the stress of routine child care raise a slew of challenges for mothers in their day-to-day activities (Mobarak et al., 2000). In cerebral palsy, the injury and damage to the brain is irreversible. The brain does not recover in the same way that other sections of the body do. As a result, cerebral palsy will not change for the better or for the worse during the course of a person's life. Associative situations, on the other hand, may improve or deteriorate with time.

Cerebral palsy has long-term consequences, not just temporary ones. Cerebral palsy is a lifelong condition for someone who has been diagnosed with it. The birth of a kid with

cerebral palsy in a household is frequently a traumatic event for the entire family. Parents are the primary caregivers for children with cerebral palsy, and they must balance the demands of their own family as well as the requirements of the kid with cerebral palsy. When a kid has cerebral palsy, other important activities that entail motor skills and muscles, such as breathing, bladder and bowel control, feeding, and learning, can be impacted.

Individuals with activity limits may find it challenging to complete tasks, which is referred to as activity limitation. Specifically, an activity limitation encompasses all of the ways in which the execution of a daily living activity may be hampered, such as doing the activity in pain or discomfort; moving too slowly or quickly, or not at the right time and place; or acting awkwardly or otherwise not in the expected manner. Barriers to activity can range from a minor to a significant deviation (in terms of quality or quantity) from conducting activity in the manner or to the level that children without a health condition might do.

In any civilization, the family is the most basic and important unit, and children are an integral component of it. When a child is born into a family, the role of the parents changes as well. For most parents, the birth of a child is a happy moment. Parents always hope for a healthy baby who will bring them joy and pleasure. When a kid is born with a physical or developmental handicap, however, parents are astonished, concerned. It's a completely unexpected occurrence for parents. Having a disabled child has a signifi cant influence on the lives of parents. Cerebral palsy is a type of severe developmental di sorder that differs from other types of childhood disabilities. Parents' lives, particularly m others', become more stressful after having a child with cerebral palsy. After having a chi ld with cerebral palsy, they encountered various challenges. Furthermore, society and co mmunity members are under-aware of the disease, which is a source of regret these days.

CHAPTER-III

METHODOLOGY

3.1 Study Design:

Qualitative study was chosen to conduct the study and as appropriate to achieve the aims was to identify the barriers experiences by parents of cerebral palsy child when they participating daily physical activity. The semi-structured questionnaire was used and face to face interview was conducted. Qualitative research is suitable for the participants to express their view and feelings. That's why researcher selected the qualitative research approach, which helps to gain understanding and exploring the feelings, opinion of parents about barriers of participating in daily physical activity of children with cerebral palsy. The design has used to focus on the parents perception of barriers on daily physical activity of cerebral palsy child. It also helps to identify the beliefs people hold and the perception of them from different perspectives. The researcher thought that this design was appropriate for this study because the parents of children with cerebral palsy are a specific group of in society and the study aim is to explore the perceptions of parent's with cerebral palsy children. The researcher collected the Information of participant's opinions because each participant's opinion is unique.

3.2 Study Site:

Data was collected from the outdoor and indoor Paediatric physiotherapy unit of the Centre for the Rehabilitation of the Paralysed in Savar.

3.3 Study Population:

Parents of Cerebral palsy children.

3.4 Sample size:

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

3.5 Inclusion Criteria:

- Mothers or fathers of children with cerebral palsy who were interested to participate this study
- Parents who were willingly interested to participate.

- All consecutive cerebral palsy patients aged between 3 years to 10 years
- All types of cerebral palsy were included
- Both boys and girls were included
- Participants who were able to communicate and had no hearing problems were selected for the study. Clear communication was required to provide answer during the interview session.

3.6 Exclusion criteria:

- Unwilling parents
- Child who had other pediatric condition
- Parents who are medically unstable
- Parents who have cognitive problem

3.7 Sampling Tools or materials:

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

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

3.8 Data Collection Procedure:

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

3.8.1 Data collection instrument:

Semi-structured open ended questionnaire.

3.8.2 Procedure of data collection:

Semi-structured interview questions were used in this study. The interview was recording using a tape recorder by taking permission from the patient's parents. Audio tape was used to record all the interviews to discover exact feeling, attitude and emotions of the participants during interviews. The interview was conducted in Bengali as though they can understand the questions easily. Face to face interview was conducted because this may provide higher response then other data collection methods. Every interview lasted for 08-12 minutes. Interview continued until saturation point was reached, that is no major new insights were being revealed and there was repetition of the same issues with different respondents. Each data was collected carefully and confidentially was maintained. Each percipient provide particular time to collect data. Each questionnaire took approximately 07-10 minutes to complete.

3.9 Data Analysis:

The data analysis mainly involved the transcript of the interviews, identifying themes and then incorporating those themes into the next stage of data collection. Same questions were asked to the participants by preparing a questionnaire. The questions were analyzed as the first step of data analysis. For a better analysis, the individual responses were read thoroughly for several times to identify the actual meaning and themes from the responses. Finally five themes were listed and codes were developed from the list. According to the codes, the differences between each 10 other were detected. The codes were also defined clearly with their actual meaning. For that reason, overtime the participant's perceptions were coded carefully according to the topic. Here the researcher carefully divided the topic into some categories. Finally themes were known from each category.

3.10 Ethical Consideration:

The Research proposal was submitted to the ethical committee that Institutional Review Board (IRB) and approval was obtained from the Board. Bangladesh Medical Research Council (BMRC) and World Health Organization (WHO) guideline also were followed to conduct the study. The protocol initially approved by ethical review committee of Bangladesh Health Professions Institute (BHPI) Savar, Dhaka. Written informed consent was taken at the time of enrolling the respondents. However verbal consent was taken when required. In consent form, the title, aim of the study, data collection procedures, required time for data collection, confidentiality and anticipated use of the result of the study was written in plain and simple Bangla language and it was brief to each respondent before data collection. All respondents were informed that they are free to leave or to refuge to take part in this study at any time. The personal information of the respondents was kept totally confidential. The information given by the respondents were analyzed using code number so that nobody can identify them.

3.11 Rigour of the study:

Researcher always tried to maintain trust worthiness and honesty in this study. The study was conducted in a clear & systematic way to reducing the sources of error and bias. During conduct the study every section of the study is checked & checked by the research supervisor. All the raw data was collected from appropriate sources and maintained referencing system.

CHAPTER-IV

RESULTS

A qualitative study results were analyzed by content analysis. By using this analysis process, the researcher organized collected data according to categories, coding and themes. The aim of the study was to identify the Parents view on barriers of participating in daily physical activities of the children with cerebral palsy. Participants respond according to their perception. In this section coding was used to understand the participants' statement and to generate the themes. At each table interview findings were described with coding. Under the different categories parent's different opinion is different codes. The tick was given only for those columns where the parents spoke positive about those issues. Here 'P' was used for participant and 1, 2, 3.... indicate participant's number.

Code Name of Participants

Participants number	Code name
1	P1
2	P2
3	P3
4	P4
5	P5
6	P6
7	P7
8	P8
9	P9
10	P10

Table-1: Code name of participant

4.2 Participant's Socio-demographic information

In this study among 10 participants the mean age was 29.5 years with age range 22-54 years. Most of the participants about four participants were lived in nuclear family whereas six participants in extended family. Three participants lived in urban areas and seven participants about lived in rural area. Among the cerebral palsy child's parents both father and mother and one grandmother were included in this study, 08 were mother, 01 were father and 01 were grandmother. The educational level among the 10 participants, 02 participants had no education, 02 participants had primary education, 03 participants had completed secondary education, 02 participants had higher secondary education, and 01 participant had Bachelor degree. Among the 10 participants 07 mothers were housewife, 02 mother garments worker, 1 father was service holder. Code name was used for all of the participants (Table-1).

Socio-demographic Information	Number of the Participants (n)
Age	
22-34	3
25-44	6
45-54	1
Sex	
Male	1
Female	9
Family type	
Nuclear family	4
Extended family	6
Living area	
Rural area	7
Urban area	3
Education level	
Illiterate	2
Primary	2
S.S.C	3
H.S.C	2
Honor	1
Occupation	
Housewife	7
Garments worker	2
Service holder	1

Table -2: Socio-demographic information of the participant

It had been possible to understand the participant opinions by content analysis, where some categories have been found. Under the different categories, patient different opinions are expressed by different codes. Five major categories were found these are

Theme that emerged from data analysis are given below

Theme-1: Lack of awareness about the condition of cerebral palsy

Theme-2: Self-care activities were done by parents

Theme-3: Child had difficulty in activities as per developmental millstone

Theme-4: Family members, relatives, neighbor and other people in the community were not co-operative

Theme-5: Psychological behavior did not create barrier during daily physical activity.

Theme-1: Lack of knowledge about the condition of cerebral palsy

Category- knowledge about cerebral palsy

Coding	No knowledge	Having knowledge
P1	-	\checkmark
P2	\checkmark	-
P3	\checkmark	-
P4	\checkmark	-
P5	\checkmark	-
P6	\checkmark	-
P7	-	\checkmark
P8	\checkmark	-
P9	\checkmark	-
P10	-	\checkmark
Total: 10	07	03

Table -3:	knowledge	about cereb	oral palsy
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According to the transcripts, among 07 participants don't have any kind of knowledge about the condition of cerebral palsy. 03 participants have little knowledge about this condition but after their child birth they have enough knowledge about this condition.

Theme-2: Self-care activities are done by parents

Category 2- About self-care activity

Table-4:	Self-care	activities
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Coding	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10	Total
Eating food by own	-	-	~	-	~	-	_	-	-	~	03
Putting clothes by own	-	-	~	_	-	-	-	-	-	-	01
Doing toilet work by own	-	-	-	-	✓	-	-	-	~	-	02

According to the transcripts, among 07 participants reported that their child is not eating food by their own, 09 participants reported that their child can't put clothes by their own and 08 participants reported that their child can't do toilet work by their own. Their child needs family member help for doing these activities.

Theme-3: Child has difficulty in activities as per developmental millstone

Category-3: Developmental millstone

Coding	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10	Total
Rolling	~	✓	~	~	~	~	~	~	~	~	10
Lying to sit	-	~	~	~	-	-	-	✓	~	~	06
Sitting	-	-	~	-	✓	-	~	✓	~	~	06
Sitting to stand	-	-	-	-	-	-	-	-	-	-	00
Standing (with support)	-	-	-	-	-	-	~	~	-	-	02
Walking	-	-	-	-	-	-	-	-	-	-	00

 Table-5: Developmental millstone

According to transcript, participants reported that all children do rolling but 06 children can lying to sit, 06 children can self-sitting, none of them can sitting to stand, only 02 can stand and none of them can't walking. As a result of this delay, the developmental millstone creates significant barriers to daily physical activity.

Theme-4: Family, Relatives, neighbor and other people in the community are not co-operative

Category: Cooperativeness from family, relatives, neighbors and other community people

Coding	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10	Total
Family members are co-operative	~	~	-	~	~	~	-	~	-	~	07
Relatives are co-operative	~	~	-	-	~	~	-	~	-	-	05
Neighbors are co-operative	~	~	-	~	-	-	-	~	-	-	04
Community peoples are co-operative	~	~	-	~	-	-	-	~	-	-	04

Table-6: Cooperativeness from family, relatives, neighbors and other community people

According to transcription, among 03 participants reported that their family members are not cooperative, 05 reported that their relatives are not cooperative, 06 reported that their neighbors are not cooperative and 06 reported that their community people are not cooperative. This unwillingness to cooperate creates a barrier for their child in participating in regular physical activity.

Theme-5: Psychological behavior don't create barrier during daily physical activity. Category: Psychological behavior

Coding	Create barrier	Doesn't create barrier					
P1	-	✓					
P2	-	√					
P3	-	√					
P4	✓	-					
P5	-	√					
Рб	-	✓					
P7	-	√					
P8	-	√					
P9	-	√					
P10	-	✓					
Total: 10	01	09					

Table-7: Psychological behavior

According to transcription, among 09 participants reported that psychological behavior don't create barrier during daily physical activity of their child and 01 participant reported that psychological behavior create barrier during daily physical activity of her child.

CHAPTER-V

DISCUSSION

In this chapter the results of the study were discussed in relation to the research questions and objectives of the study. It has been possible to understand the parents view on barriers of participating daily physical activity. By content analysis different categories were found under which different opinions were expressed by different codes. Five major categories were found under five seven themes were emerged. This part was carried out on the basis of analysis of acquired data and its relevance with other published literature related to the study.

Summary of theme that emerged from data analysis:

Theme-1: Lack of awareness about the condition of cerebral palsy

Therefore, lake of awareness about the condition of cerebral palsy plays a negative effect on the participating daily physical activity. During interview, most of the participants told they didn't know about the condition.

Participant -1, 7, and 10 said,

They heard, saw this condition but didn't know the name of this condition. After being admitted or after taking therapy session in CRP, They had clear knowledge about cerebral palsy.

"I heard about this disease name from his friend. My friend child also has this condition".

"I saw this kind of illness but she didn't know the name. After being admitted in CRP, I know more that it occurs after head injury".

Participant -2, 3, 4, 5, 6, 8, 9 said,

They never had an idea before about this condition. They said this problem that occurs when the baby is injured before or during the birth or after birth problems knows this after admitted or taking therapy session here. And also known the name of this condition after that. One participant was told she had never heard or seen any kind of disease like this. "I never heard about this condition. I have never heard or seen any kind of disease".

"I have not heard the name of this disease before. I have been seeing such diseases since my child were born".

Theme-2: Self-care activities are done by parents

From the transcripts among eight participants reported their child need help from family members for eating, dressing, toileting, bathing combing and two participants reported their child need little bit help for doing eating, dressing, toileting, bathing and combing.

Participant-1, 2, 4, 8, 9, 10 said,

Their child couldn't do anything on his own. I had to take care her/him all self-care activity like bath, feed, put on clothes. She/he had a problem with brain that's why she/he didn't understand, so she/he couldn't did her jobs.

"My child can't do any work on his on, I have to do all the works like bathing, feeding, taking him to the toilets all kind of self-care work"

Participant-3, 5 said,

Their child could do some things themselves and some things did by parents. For example, he could eat by himself, he couldn't wear pant but he could wear shirt and Parents just sit and bring him from bathroom other bathroom work he could do by himself.

"My child do something by his own and something done my me"

Participant-6, 7 said,

Parents had to feed, putting cloth him. Their child had tries on his to do self-care activities but couldn't do more things like normal kinds.

Theme-3: Child has difficulty in activities as per developmental millstone

In my study almost all of participants reported their child have delay development for doing any kind of activity.

Participant said similar,

Child couldn't do any physical work in a good way. Everything learns later than normal child. They couldn't sit, couldn't stand, couldn't walk, and couldn't go one place to another place in a proper way. They take lot of help for done this works. People of the family member help them to this entire works.

"My baby can't do anything. She can't move from one place to another while sitting. Child can't crawl. Can't stand up, Can't move hands normally. That's why I said I can't do any work. Just can get up from bed and stand-up"

Theme-4: Relatives, neighbor and other people in the community are not co-operative

Family members of children with cerebral palsy have to faces some social suffering. Some relatives, neighbor and other social people are enough sympathetic towards them but most of the people are not co-operative. It was moreover supported by writing that the community individuals frequently recognized parents adversely and parents were stigmatized and faulted for having a child with disability (Yousafzai et al., 2011). When parents go outside of their house with their children, such kind of negative attitude and negative talking create barrier for them.

Participant- 1, 2, 4, and 8 said similar

Everyone sees their baby in a normal way. Relatives love them, look like their normal children. Neighbor's also love them. Don't talk nonsense about their child. Even neighbor's let their child play with their child. No one makes a bad comment even when they take them somewhere outside.

"My baby behave as like normal baby when I take the favorite things from her hand she crying otherwise she don't even bother"

Participant- 3, 5, 6, 7, 9 and 10 similar

Though their baby is sick no one looks at them well. No one but their own family speaks negatively. Their child always compare with normal child when he/she go outside. But neighbor's let their children play with their child willingly.

"My child has been three years, in these three years I have not gone anywhere other than my mother home. People say a lot of negative things when they see my baby go out. I feel bad so that I just go my mother's home. Everyone in the mother-in-law's house talks a lot. Don't caress my baby"

Theme-5: Psychological behavior don't create barrier during daily physical activity.

Nearly all participants said similar

Child's behavior is normal. Don't cry too much, don't get too angry, don't fight also don't shout too much. Their behavior is normal when playing with other children. The child's behavior is normal even when they doing daily activities. So, psychological behavior is not a barrier for cerebral palsy child when they doing daily physical activity.

One participant said,

"My child's behavior is sometimes good and sometimes not good. Because of that I can't do any work for him sometimes. He gets angry quickly and fights"

In this study, 10 parents' perception is taken for find out the barriers of daily life when their cerebral palsy child doing daily physical activity. The aim of the study was to assess perceptions of parents about barriers of participating daily physical activity of children with cerebral palsy. The study's findings have met the research project's objectives. To generate the result, more samples should be taken, with the goal of making it more valid and dependable. In future researchers, the outcome or result can be measured using a reliable scale. Samples should be collected from a variety of Bangladeshi institutions. It should take more time to properly generate this research. This is an undergraduate study, and conducting the same research at the graduate level would yield more exact outcomes. The study had limitations, it is suggested that those limitations will be overcome during additional research.

Although this study identified important barriers to physical activity participation, it had limitations. The study used a small, convenience sample of parents and children with CP, although the sample size of parents was within the recommendations for methodology. The results of the present study only reflect stories from this specific area. Furthermore, like other qualitative studies, the results may not be generalizable to other families and children with CP; however, the results can provide insight into physical activity barriers for this specific diagnosis.

The findings might also offer other communities some understanding of the perceptions of families as they engage stakeholders to find solutions to the challenges associated with physical activity access among youth living with a disability. Incorporating more opportunities for families, children with CP and other mobility impairments to develop specific programing is crucial to ensure accessibility of programs, equipment, and public spaces. The development of awareness campaigns and community education is a starting place for advocacy efforts to design inclusive environments all areas.

This study represents an important first step to understand barriers in community and provides a foundation for local change and fills a unique niche in the literature. Currently, there is limited objective evidence on physical activity levels of children with CP in environments. There is a disparity in the published evidence on physical activity and related research in typically-developing children compared to children with CP and mobility limitations. There is a need for intervention-based studies to improve physical activity in individuals with CP.

Limitation:

To make a successful research it might be time consuming. As I got short period of time to complete the research, I had to take small sample size that is 10. If large number of sample size was taken, it would be more effective.

Only 10 samples do not represent the main barriers for participating daily living activity.

The sample was collected only from CRP. If it was collected another many institutes, the result would be more reliable and appropriate and also give a clear perception of parent's about barriers.

As Sample size was not large number, I could not show it in percentage.

As it was the first research of the researcher so there might be some mistakes that should be overlooked by the supervisor and the honorable teachers

CHAPTER-VI CONCLUSION AND RECOMMENDATION

6.1 Conclusion

Cerebral palsy is a neurological disorder. A child with cerebral palsy faces many obstacles when they participating daily physical activity. Low levels of physical activity are a worldwide threat to the health of children, including those with disabilities. For this reason, need to find out the hindrance that limits their daily physical activity. This study comprehends about the experienced barriers in the daily physical activity when participants child participating among their child with cerebral palsy faced lacking of the knowledge about cerebral palsy of their parents, can't doing self-care activity, delayed developmental millstone, confronted the prejudice and social stigma about their condition and their psychological behavior. Although cerebral palsy affects a child with a residual condition, they can reintegrate if the identified barriers can really be overcome. As a result, identifying these barriers will facilitate the creation of a strategy for overcoming them. So, if these barriers are minimized or overcoming strategies are developed and implicate, these child with cerebral palsy can improve their quality of life. The government should step forward to assist in the organization of a public awareness and promotional program on cerebral palsy and its treatment in order to raise community understanding about cerebral palsy and its treatment.

6.2 Recommendation

From the findings of this study, the majority of participants who did visit CRP's pediatric department at the time of this research identified some barriers. It is suggested that further quantitative study should be conducted on a large group of people from various districts and geographical locations of Bangladesh, as well as finding out how to overcome difficulties experienced by children with cerebral palsy. The sample should be representative of the population as a whole. The results will be more significant if the researcher does a long-term study.

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Appendix

<u>অনুমোদন পত্র</u>

আসসালামু আলাইকুম,

আমি রুকাইয়া ইসলাম ইলা 'বাংলাদেশ হেলথ প্রফেশন্স ইন্সটিটিউট এর চতুর্থ বর্ষের একজন ছাত্রী। আমি একটি গবেষণা করছি যার শিরোনাম হল "প্যারেন্টস ভিউ অন ব্যারিয়ারস অফ পারটিসিপ্যাটিং ইন ডেইলি ফিসিক্যাল আক্টিভিটি ইন চিলড্রেন উইথ সেরেব্রাল পালসি" এই জন্য আমি আপনার কাছে কিছু প্রশ্নের উত্তর জানতে চাচ্ছি, যেটাতে সর্বমোট ৮-১২ মিনিট সময় লাগবে। এটাও নিশ্চিত করছি যে আপনি যেসব তথ্য প্রদান করবেন তার গোপনীয়তা বজায় থাকবে।

এখানে অংশ গ্রহন আপনার নিজ ইচ্ছার উপর নির্ভর করে। আপনি চাইলে অংশগ্রহণের পর যে কোন সময় কোন ফলাফল ছাড়া চলে যেতে পারেন। এছাড়া যদি আপনার এই গবেষণায় অংশ গ্রহণকারী হিসেবে কোন প্রশ্ন থাকে তাহলে আপনি আমার অথবা আমার সুপার ভাইজার মোঃ মিল্লাত হোসেন (এসিস্ট্যান্ট প্রফেসর, প্রজেক্ট এন্ড কোর্স কো-অর্ডিনেটর ডিপার্ট্মেন্ট অব রিহ্যাবিলিটেশন সাইন্স, সি.আর.পি, সাভার, ঢাকা) সাথে যোগাযোগ করতে পারেন।

গবেষণাটি শুরু করার আগে আপনার কোন প্রশ্ন আছে ?

আমি কি আপনার অনুমতি পেয়ে এই সাক্ষাৎকারটি আরম্ভ করতে পারি ?

হ্যা.....

না.....

গবেষকের স্বাক্ষর ও তারিখঃ

স্বাক্ষীর স্বাক্ষর ও তারিখঃ

Consent Form

Assalamulaikum,

I am Rukaiya Islam Ela, 4th year student of B.Sc. in Physiotherapy in Bangladesh Health Profession Institute. I am conducting a research and the title is **"Parents view on barriers of participating daily physical activities of the children with cerebral palsy"** which is included in my course. For that I'm asking you to answer some questions, which will not take time more than 08-12 minutes. It also ensures that the information you provide will be kept confidential.

Participation here depends on your own will. If you want, you can skip your name from the list of participants at any time. In addition, if you have any questions as a participant in this study or if there is any problem, you can contact with me or Muhammad Millat Hossain, Assistant Professor Department of Rehabilitation Science, CRP, Savar Dhaka.

Do you have any questions before starting the research?

Can I start this interview with your permission?

Yes.....

No.....

Participant's signature and date

Witness's signature and date.....

<u>প্রশ্নপত্র (বাংলা)</u>

- পর্ব -১: সামাজিক-জনসংখ্যাতাত্ত্বিক তথ্য
- ১. আইডি নং:
- ২. অংশগ্রহণকারীদের নাম:
- ৩. বয়স:
 - ক. অংশগ্রহণকারীর বয়সঃ
 - খ. বাচ্চার বয়সঃ
- 8. लिञ्र:
 - ক. পুরুষ
 - খ. মহিলা

৫. শিক্ষাগত যোগ্যতা :

- ক. আনুষ্ঠানিক শিক্ষা নেই
- খ. প্রাথমিক বিদ্যালয়ের চেয়ে কম
- গ. প্রাথমিক সমাপ্ত
- ঘ. জেএসসি সম্পন্ন
- ঙ. এসএসসি সম্পন্ন
- চ. এইচএসসি সম্পন্ন
- ছ. স্নাতক সম্পন্ন
- জ. মাস্টার্স সম্পন্ন
- **৬. (ମ**୍ମମା:

৭. আবাসিক এলাকা:

ক. শঙ্করে

খ. গ্রামীণ

৮. পরিবারের ধরনঃ

- ক.অণু পরিবার
- খ.যৌথ পরিবার

পার্ট -২: এই অংশটি দৈনন্দিন শারীরিক ক্রিয়াকলাপে অংশ নেওয়ার ক্ষেত্রে সেরিব্রাল প্যালসি আক্রান্ত শিশুদের পিতামাতার বাধা অন্বেষণের জন্য ডিজাইন করা হয়েছে।

১. সেরিব্রাল প্যালসির অবস্থা সম্পর্কে আপনার কি কোনো জ্ঞান আছে?

২. আপনার শিশুর কোন সমস্যা হচ্ছে যখন সে সেলফ কেয়ার অ্যাক্টিভিটি করছে?

হাাঁ
 না

তিনি কি ধরনের সমস্যার সম্মুখীন হন দয়া করে ব্যাখ্যা করুন।

ক) আপনার বাচ্চাকে খাওয়ানোর সময় আপনার কি কোন সমস্যা হচ্ছে? যদি আপনার কোন সমস্যা হয়, দয়া করে আমাকে বলুন আপনি কোন সমস্যার সম্মুখীন হচ্ছেন।

খ) আপনার বাচ্চার কাপড় পরার সময় কি কোন সমস্যা হয়? যদি হ্যাঁ, তাহলে দয়া করে ব্যাখ্যা করুন।

গ) এবং যদি সে/সে তার কাপড় পরতে না পারে বা অন্য কারও সাহায্য নিতে পারে? অনুগ্রহ করে বর্ণনা করুন.

৩. আপনার সন্তান কি দৈনন্দিন শারীরিক ক্রিয়াকলাপে সক্রিয়? দৈনন্দিন শারীরিক ক্রিয়াকলাপ মানে বসে থাকা, হাঁটা, স্ব-ব্যায়াম।

> ০ হ্যাঁ ০ না

ক) যদি সে এই ক্রিয়াকলাপটি করতে না পারে এবং সমস্যার সম্মুখীন হয় তবে দয়া করে আমাকে বলুন যে সে কোন ধরণের বাধার মুখোমুখি হয়। ৪. তারা কি সামাজিক পরিবেশ দ্বারা গ্রহণ করেছে যা তাদের জন্য ইতিবাচক? যদি না তাহলে তারা কোন ধরনের বাধার সম্মুখীন হয় দয়া করে আমাকে বলুন।

হ্যাঁ
 না

ক) সমবয়সীদের দ্বারা গ্রহণ করা হচ্ছে না? এর পিছনে কারণ কি মনে করুন দয়া করে ব্যাখ্যা করুন?

খ) অন্যের পিতামাতার দ্বারা গৃহীত হচ্ছে না বা নির্যাতিত হচ্ছে? অনুগ্রহ করে বর্ণনা করুন।

৫. আত্ম-যত্ন, শারীরিক বা যোগাযোগমূলক ক্রিয়াকলাপ করার সময় তিনি কী ধরণের মানসিক আচরণ দেখান। দয়া করে ব্যাখ্যা করুন।

৬. আপনার সন্তানদের জন্য পরিবার, বন্ধু এবং অন্যদের সাথে যোগাযোগের বাধা সম্পর্কে আপনার ধারণা কী? দয়া করে বর্ণনা করুন।

৭. আপনার বাচ্চাদের খেলাধুলার ক্রিয়াকলাপগুলির প্রতিবন্ধকতা সম্পর্কে আপনার ধারণা কী?

Questionnaires (English)

Part-1: Socio-demographic information

- A. ID No:
- **B.** Name of the participants:
- C. Age:
- D. Sex:
 - o Male
 - o Female

E. Educational level:

- No formal education
- o Less than primary school
- Primary completed
- o JSC completed
- SSC completed
- HSC completed
- o Graduate completed
- Masters completed

F. Occupation:

G. Residential area:

- o Urban
- o Rural

H. Family type:

- Nuclear family
- Extended family

Part-2: This part is designed to explore barriers by the parents of children with cerebral palsy participating in the daily physical activities.

- 1) Do you have any knowledge about the condition of cerebral palsy?
- 2) Are your baby having any problem when he/she doing self-care activity?
 - o Yes
 - \circ No

Please explain what kind of problems s/he faces

- **a.** Are you having any problems when you feeding your baby? If you are having problems, please tell me what problems you are facing.
- **b.** Does your child have any problems while wearing his clothes? If yes, then explain please.
- **c.** And what if s/he can't wear her clothes or has to deal with someone else's help? Please describe.
- Are your children active in daily physical activity? Daily physical activity means sitting, walking, self-exercise.
 - YesNo
 - **a.** If she can't do this activity and facing a problem please tell me what kind of barricades s/he faces.
- 4) Are they accepted by the social environment which is positive for them?

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YesNo
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- **a.** Not being accepted by peers? What's the reason behind that think please explain?
- **b.** Not being accepted by other's parents or being bullied? Please describe.

- 5) What is your perception on the barriers of communicate with family, friend and others people for your children. Describe please.
- 6) What is your perception on the obstacles of your children with playful activities?
- 7) What kind of psychological behavior he/she show when doing self-care, physical or communicative activity. Please explain.

Approval of Thesis Proposal



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

(The Academic Institute of CRP)

Ref:

CRP/BHPI/IRB/06/2021/479

Date:

17/06/2021

To Rukaiya Islam Ela B.Sc. in Physiotherapy Session: 2015-2016, Student ID: 112150312 BHPI, CRP, Savar, Dhaka-1343, Bangladesh

Subject: Approval of the thesis proposal "Parents view on barriers of participating in daily physical activities of the children with cerebral palsy" by ethics committee.

Dear Rukaiya Islam Ela,

Congratulations.

3

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

Sr. No.Name of the Documents1Dissertation proposal2Questionnaire (English & Bengali version)

Information sheet and consent form

The purpose of the study is to find out the barriers of daily physical activity of children with Cerebral Palsy. The study involves use of a questionnaire to find out the barriers of daily physical activity and there is no likelihood of any harm to the participants. Data collectors will receive informed consents from all participants. Any data collected will be kept confidential. The members of the Ethics committee approved the study to be conducted in the presented from at the meeting held at 8.30AM on 1st March, 2020 at BHPI (23rd IRB Meeting).

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

Best regards

behanaer

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

CRP-Chapain, Savar, Dhaka-1343, Tel : 7745464-5, 7741404 E-mail : principal-bhpi@crp-bangladesh.org, Web: bhpi.edu.bd, www.crp-bangladesh.org

Permission Letter

Date: 16.06.21

Head

Department of Physiotherapy

Centre for the Rehabilitation of the Paralysed (CRP)

Chapain, Savar, Dhaka. -1343.

Through: Head, Department of Physiotherapy, BHPI.

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

Sir.

4th year

With due respect and humble submission to state that I am Rukaiya Islam Ela, a student of 4th year B.Sc. in Physiotherapy at Bangladesh Health Professions Institute (BHPI). The Ethical committee has approved my research project entitled: "Parents view on barriers of participating in daily physical activities of the children with cerebral palsy" under the supervision of Assistant Professor Muhammad Millat Hossain, Dept. of Rehabilitation Science BHPI. I want to collect data for my research project from the Paediatric, Department of Physiotherapy at CRP. So, I need permission for data collection from the Paediatric Department at CRP (CRP, Savar, Dhaka. -1343). I would like to assure that anything of the study will not be harmful for the participants.

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

ghe will collect data. two Dept. please he Yours faithfully. Rukaiya Islam Rukaiya Islam Ela Recommended shohi B.Sc. in Physiotherapy Class Roll: 41, Session: 2015-16 16.06.2021 Md. Shofiqul Islam Bangladesh Health Professions Institute (BHPI) Associate Professor & Head Department of Physiotherapy Bangladesh Health Professions Institute (BHPI) (An academic Institution of CRP) CRP, Chapain, Savar, Unaka-1343 CRP-Chapain, Savar Dhaka. +134