UNDERSTANDING THE LEVEL OF CAREGIVER BURDEN ON CAREGIVER OF SCHOOL ATTENDING CEREBRAL PALSY CHILDREN AT WILLIAM AND MARIE TAYLOR SCHOOL CRP-BANGLADESH

By

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SUPERVISOR'S STATEMENT

As supervisor of Rajan Tamang, M.Sc. Thesis work, I certify that I consider his thesis **"Understanding the level of caregiver burden on caregiver of school attending cerebral palsy children at William and Marie Taylor School CRP-Bangladesh"** Is a bonafide research work done by Mr. Rajan Tamang in partial fulfillment of the requirements for the degree of M. Sc. in Rehabilitation Science.

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Declaration Form

- This work has not previously been accepted in substance for any degree and is not concurrently submitted in candidature for any degree.
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Date: 20th, May 2018 Signature of the Candidate

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List of Acronym

BHPI- Bangladesh Health Professional Institute

BMRC- Bangladesh Medical Research Council.

CRP- Centre for Rehabilitation of Paralyzed.

CBSS- Caregiver Burden Score Scale

CP- Cerebral Palsy

EEG- Electroencephalography

IRB- Institution Review Board

MRI- Magnetic Resonance Imaging

QOL- Quality of Life

SD- Standard deviation

WHO- World Health Organization

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ABSTRACT

Cerebral palsy is chronic motor disability with huge economical burden as well as creating fatigue on caregiver arising in early childhood. Caregiving burden is essentially characterized by an understanding of overload everyday care; support on child's feeding to every behavior those results from an imbalance of perceived demands and resources, which may ultimately lead to feelings of helplessness and one, can perceive the burden. The main objective of this study was to identify the level of caregiver burden on school attending cerebral palsy (cp) children. Research methodology was a descriptive cross-sectional study design was implied to conduct the research as this study aimed to evaluate the extent of caregiver burden of caregiver of school attending CP children. The total sample included was 54 respondents. Outcome measure was semi-structured self prepared Caregiver Burden Score Scale (CBSS) questionnaire. Data was analyzed using spss (statistical package of social science) 16.0 versions for descriptive statistics, chi square test, Crosstab to test the association between different study variables. The mean age of participants was mean age (μ=32.91 years and (SD= 6.094). Mean score of caregiver burden was 2 near to moderate level and standard deviation of score was 0.336. There was only association between number of child and caregiver burden score (0.044) which was less than the p-value (0.05). This study concluded that caregivers are severely affected on coping with environmental situation while transferring cp child to school.

Key Words: Cerebral Palsy, caregiver, burden, environmental domain, disable child.

CHAPTER-I INTRODUCTION

1. Background

It is estimated incidence of 2 to 2.5 per 1000 live birth worldwide (Blair., 2010). In the united state of America there exist about 5.9 million children living at home because of their severe disability (Wylie et al., 2013). Prevalence of cerebral palsy in south Asian population is 1.09 per 1000 children (Tess C. Lang, BS, et al., 2012). Bangladesh is highly populated country in south East Asia and there exist approximately 2.6 million children with moderate to severe disability but unfortunately only 1500 children are access with especial education provided by the government (Ackerman P, Thormann MS and Huq S. 2013).

According to the reports of world health organization (WHO) prevalence of 'severe disability' on the age of (0-14) children as 7/1000 (Wylie, et al., 2013), it was an estimated 93 million children around the globe in seek of service delivery in institution or community based to maintain or to cure their disabilities (Murthy et al., 2014). A recent surveillance study done in Bangladesh showed increased prevalence of cerebral palsy 3.7/1000 (Khandaker et al., 2015).

However, all the children with moderate or severe cp have certain regular caregiver burden, but in addition school attending cp children impose extra loaded caregiver burden. The main aim of this thesis is to find out the additional caregiver burden amongst the primary carer of school attending cerebral palsy children.

Cerebral Palsy (CP) is defined as an "umbrella term covering 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", The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication and behavior, by epilepsy, and by secondary musculoskeletal problems (Leonard, J., & Graham, H. K. 2009).

Caregivers of children with CP require more attention and longer duration of care, these excessive responsibility can negatively affects their physical, psychological and social health (Pushpa, R. A. (2015). Mother of children with CP suffers from depression, grief, disbelief, fear, hopelessness and feelings of inability to cope for their children with long-term disability (Al-Gamal, 2013). A study conducted in Bangladesh by Mubarak and colleagues, they reported that psychiatric morbidity rate is 41.8% in mothers of 91 children with CP (Gleen *et al*. 2009). CP children have pattern of sleep disturbances, which affect their caregiver's quality of sleep as well (Marx, 2011*)*. Poor sleep quality is associated with higher levels of depression. According to Diagnostic and Statistical Manual of Mental Disorders (DSM IV) sleep impairment is part of the diagnostic criterion for depression disorder and sleep trouble is a risk factor for depressive symptoms (Marx, 2011).

CP is chronic motor disability with huge economical burden as well as creating fatigue on caregiver arising in early childhood (Hai et al., 2016). 'Cerebral' refers to the brain and 'palsy' means weakness or non functional lack of muscle control (Australia & C. P. 2008). CP is known as little`s disease for many years, because initially it was noticed by English surgeon William Little in the 1860s, seen in early child hood with spastic muscles in their legs and give rise to some degree in their hands (Hai, et al., 2016). It is a chronic condition defined as a set of functional limitations due to alterations in the development of the central nervous system (Rethlefsen, et al., 2010).

Generally CP is associated with co morbidity, cognitive and sensory disorders resulting from disturbance in the development of an infant or fetal brain, which remain life-long of the patients (Mbugua et al., 2011). CP is major cause of primarily a disorder of movement and posture leading to moderate to severe disability (CDC, 2010).

The main causes of cerebral palsy as, (a.) injure to the white matter of the brain; causes include genetic, viral, or environmental, such as prenatal exposure to toxic substances, child abuse, or improper use of a car restraint that results in damage to the white matter of the brain, (b. improper development of the brain; causes include viral or genetic, (c.) abnormal bleeding in the brain; causes include environmental, such as maternal or child abuse that results in a brain bleed, and random internal occurrences such as a stroke. (d.)Brain damage caused by hypoxia due to cord around the neck, leads to birth trauma or placental rupture and forceps delivery (NINDS, 2010).

Overall these types diagnosis can be confirmed on a Magnetic Resonance Imaging (MRI). Occasionally, a diagnosis of CP is made despite no abnormalities evident on an MRI. Severe cases of CP are usually evidenced by abnormalities on an MRI and an electroencephalography (EEG) as many children may have co-morbid seizure disorders (NINDS, 2010). Factors associated with an increased risk of CP include older maternal age, illiteracy, male gender, and preterm birth, and low birth weight, infection during pregnancy and high grade fever to mother (Vargus et al., 20011). Even though motor malfunction is the major limitation of CP, the severity of disability is also determined by the presence of cognitive, sensory and social impairments (Bottcher et al., 2010).

Cerebral palsy can be either congenital or acquired after the birth as many as 90% of CP cases have unknown etiology and are assumed to be congenital in nature (NINDS, 2010). Another example of congenital CP includes asphyxia during the birth process, which is estimated to only account for 5 to 10% of all CP cases (NINDS, 2010). A small percent of children have acquired CP, which occurs from a postnatal insult (NINDS, 2010). Several medical conditions cause postnatal CP, including meningitis, viral encephalitis, severe jaundice, and stroke (CDC, 2010; NINDS, 2010).

Behavior problems of school attending CP children are an important predictor of caregiver psychological well-being, both directly and indirectly, through their effect on self-perception and family function, the psychological and the physical health of the caregivers, the practical day-to-day needs of the child created challenges for parents (Mbugua et al., 2011). Providing care is part of parenting, it can often generate a considerable burden when the requirements are excessive and long lasting. The regular and consistent excessive responsibility may adversely affect the physical and psychological health of caregivers (Brehaut et al., 2009) also disturbing their social, cultural and professional lives (Grootenhui et al., 2009) and perhaps they will have poor quality of life (Davis et al., 2010).

Classification of CP in regards to topography is monoplegia, hemiplegia, diplegia and quadriplegia Monoplegia and triplegia are relatively uncommon. There is a substantial overlap of the affected areas. In most studies, diplegia is the commonest form (30% – 40%), hemiplegia is 20%- 30%, and quadriplegia accounting for 10% -15% (Alcassa et al, 2013 and Sanker and Mundkur, 2005).

According to (NINDS, 2010) CP can be classified on the basis of brain injury and which leads to more than one character on children causing additional severity as:

Spastic Hemiplegia: usually affects the arm, hand, and leg on one side of the body. Their intelligence is usually in the normal range; however they may have speech delays and impairments. Children with this type walk later and on their tip-toes, because of tight heel tendons, which can be released by surgery, greatly reducing their affectedness.

Spastic Diplegia: is identified by muscle stiffness predominantly in the legs and less severely affects the arms and face, although the hands may be clumsy. Children with this kind of CP may require a walker or leg braces. Intelligence and language skills are generally normal.

Spastic Quadriplegia: is the most severe form of CP, and often is accompanied with moderate to severe mental retardation. This form is caused by widespread damage to the brain or significant brain malformations. Children will often have severe stiffness in their limbs but a floppy neck or trunk. They are rarely able to walk. Speaking and being understood are difficult. Seizures can be frequent and hard to control.

Dyskinetic: is characterized by slow and uncontrollable writhing movements of the hands, feet, arms, or legs. In some children, hyperactivity in the muscles of the face and tongue makes them grimace or drool, intelligence is rarely affected in these forms of cerebral palsy.

Ataxic cerebral palsy is a very rare form of CP that affects balance and depth perception. Children will often have poor coordination and will walk unsteadily with a wide-based gait, placing their feet unusually far apart; sometimes it is pronounce as drunken gait pattern (NINDS, 2010)

As nurturing and providing care is part of parenting by parents, it can often cause a significant burden when the requirements are excessive and long lasting, such excessive regular caring and responsibility may adversely affect the physical and psychological health of caregivers (Brehaut et al., 2009; Tucker, Butler, Loyuk, Desmond, & Surrency, 2009), affecting their social, cultural and professional lives (Grootenhuis & Bronner, 2009) and possibly reducing their quality of life (Davis et al., 2010). Caregiver burden has also been defined as the strain or load borne by a person who cares for a chronically ill, disabled, or elderly family member (Beyond, A. A. R. P. 2016).

It is a multidimensional response to physical, psychological, emotional, social, and financial stressors associated with the caregiving experience, caregiver burden has been defined as the type of stress or strain that caregivers experience related to the problems and challenges they face as a result of the status of the care recipient, it is the state resulting from necessary caring tasks or restrictions that cause discomfort for the caregiver (Vargus, J.I.L.D.A., 2011). Caregiving burden is essentially characterized by an understanding of overload everyday care; support on child’s feeding to every behavior that results from an imbalance of perceived demands and resources, which may ultimately lead to feelings of helplessness (Bastawrous, M. 2013).

1.2. Significance of the study

Cerebral palsy (CP) is a chronic condition defined as a set of functional limitations due to alterations in the development of the central nervous system (Rethlefsen, Ryan, & Kay 2010; Snider, Majnemer, & Darsaklis, 2010). Prevalence based study of cerebral palsy in the United States, Egypt and Taiwan have found prevalence rates above 3/1,000 live births in people 4–48 years of age (Chang et al., 2015). A recent study conducted in Bangladesh estimated prevalence of CP 3.7/100 (Khandaker et al., 2015). In 2010, approximately 65.7 million informal caregivers provided 80% - 90% of the long-term assistance in the home to children and adults with physical or cognitive limitations (Rosalyn Carter Institute for Caregiving, 2010).

Children with cerebral palsy are highly family oriented for their all activities of daily living. (Jilda V. Adam, 2011). Provision of care for a child with a long-term health condition is often associated with negative health outcomes in caregivers, for instance, depression, stress, anxiety and low self-efficacy were reported in caregivers (Davis et al., 2010). Understanding the caregiver burden, one can understand the needs of the families and identify those at risk for adaptation problems. Additionally, they mentioned that parents change over time, just as children do and by acknowledging this occurrence, professionals can attend to the burdens as they too change (Glenn et al,. 2009).

The caregivers of children with cerebral palsy are affected with direct or indirect self-perception, social support, stress management and family functioning. They get continuous care and supervision at home environment for feeding, dressing, mobility etc in all aspects of daily living. While providing such nonstop care and help in every aspect to their children with cerebral palsy, caregivers have to face many problems which are burden for them.

Caregiving burden is essentially characterized by an understanding of overload that results from an imbalance of perceived demands and resources, which may ultimately lead to feelings of helplessness (Bastawrous, M. 2013). Too much of responsibility can adversely affect the caregivers physical, psychological and social health (Brehout et al., 2009).

In addition schooling such dependent child would be further more over loaded burden to the caregiver in broad aspects. Therefore, it is imperative to find out the additional loaded burden on caregiver of school attending cerebral palsy children. It is known that the care giver burden of the children with cerebral palsy is intertwined and full of stress. But how severe is the additional burden to caregiver because on school attending cerebral palsy children is unknown.

1.3. Research Question

What is the level of caregiver burden on caregiver of school attending cerebral palsy children?

1.4. Operational Definition

Caregiver: Person who provide care to needy or to the person with disability.

Burden: It is the state of care which exceeds beyond the capacity of caregiver.

Formal Caregiver: Caregiver who provide care to the needy people with the exchange of money or goods.

Informal Caregiver: Caregiver who provide care to the needy selflessly without care of money or any returns in terms of care.

CHAPTER-II LITERATURE REVIEW

Revised definition of cerebral palsy (CP) in 2006 is ‘the motor disorders of CP are often accompanied by disturbances of sensation, perception, cognition, communication, and behavior, by epilepsy, and by secondary musculoskeletal problems’ (Rosenbaum et al., 2007). “Cerebral” means “brain” and “palsy” means “a physical disorder”, So CP means “brain paralysis.” (Mushtaq and Suman, 2014).

Prevalence based study of cerebral palsy, principally in Australia and Europe, have found cerebral palsy prevalence ranging from 1.5 to 2.5 per 1,000 live births (Parkes et al., 2008). Similarly other studies in the United States, Egypt and Taiwan have found prevalence rates above 3/1,000 live births in people 4–48 years of age (Christensen et al., 2014; El-Tallawy et al., 2014; Chang et al., 2015). However a recent study done in Bangladesh estimated prevalence of CP 3.7/100 (Khandaker et al., 2015).

CP is the major universal motor disability in children; which requires medical support, educational, social, and rehabilitative resources throughout the lifespan (Hurley et al., 2011). As a human despite of any disability, all the children with cerebral palsy are expected to live well and possible comfort (Mychild, 2013). Early 1-3 years of life, cerebral palsy is not often identified even it is a birth defected in the brain, control of the movement and posture are affected and child cannot move their body parts normally because of malfunctioning brain controls the movement (American pregnancy association, 2013). In addition, locomotion disorder is the main limitation in CP, it is also characterized by the cognitive, sensory and inappropriate social development, and these limitations lead to significant influence on self care activities like eating, mobility, clothing, and personal hygiene along with unique feature of early childhood disability (Davis et al., 2010).

Care of these children, require more attention and longer duration of care compared to the care of normal children, which results in burden on parents and family in addition, regular and excessive responsibility can adversely affect their economic status, physical health, mental health and social health (Brehout et al., 2009, Desmong and Surrency. 2009). It also affects parent’s social, cultural and professional lives (Grootenhuis and Bronner 2009). Cerebral palsy cannot be cured; however, depending on the severity of effects on muscle groups, there are treatments that can help to reduce the effects on the body, such as it includes physical therapy, occupational therapy, pharmacotherapy, surgery, and orthotic devices (CDC, 2010).

All of these techniques require extra time on the part of the caregiver, and overall can increase the amount of care needed for these children. The typical understanding of the effects of care on the caregiver should take into account both the physical and mental limitations of the person being cared for, the context in which the care occurs, the consequences arising from the caring role and the factors that may moderate all of the above. Only by taking into account all these elements simple and effective interventions can be introduced to reduce the negative effects and enhance the positive effects of care (Pousada et al., 2009).

Different authors have explained that parents of children with disability by physical or mental illness are more likely to experience burden (Fido, A., & Al Saad, S. 2013) and they experience depression, anxiety and sadness rather than parents of children without disabilities (Cheshire, A., Barlow, J. H., & Powell, L. A. 2010). The parents suffering with such mental problem have the higher chance of increased burden those have children with chronic disability (Calderón et al., 2011). Children with cerebral palsy are highly family oriented for their all activities of daily living. (Jilda V. Adam, 2011).

Depression on mother referring to World Health Organization (WHO) definition depression is very frequent mental disorder that includes depressive mood, loss of interest or please, awake the felling of guiltiness, affects the appetite, dream and concentration (Pushpa, R. A. (2015). Parents having a child with disability leads to maternal depression, child`s condition, the level of the children's emotional and behavioral problems and the level of social support available to mothers are directly associated with an increased risk of mental health problems among mothers (Ribeiro et al., 2016).

For every individual there might be a number of perceived psychosocial effects that regulate the impact of stress on health and well-being of carer, while fulfilling the role and responsible of parents, their child with long term disabilities comes on priorities along with all other family role, social role and occupational role, caregiver has to put more effort and energy and prolong doing same work and care need to be compensated with more effort, more energy finally suffering with caregiver burden(Davis et al., 2010).

Caregiving burden is essentially characterized by an understanding of overload that results from an imbalance of perceived demands and resources, which may ultimately lead to feelings of helplessness (Bastawrous, M. 2013). The Single coping strategy like behavioral disengagement, in order to further inspect a specific avoidant coping behavior that has been distinctively linked to depression, frustration, helplessness and powerlessness in different populations (Burker et al.,2010).

Similarly, parents' behavioral disengagement coping independently is directly related to their children's quality of life. Carona et al states that the mainly caregiving burden may affect parents' and their children's quality of life (QOL) through different variables or coping strategies; and the fact that the quality of life of children/adolescents with chronic conditions is directly or indirectly correlated with their parents' quality of life (Carona et al., 2013), it eventually suggests that impairment in parents' QOL due to parental maladaptive coping may finally affect the QOL of their children with a condition cerebral palsy, increased psychosocial challenges experienced by caregivers were the lack of community support, lack of information, financial constraints and transport barriers that hindered optimal rehabilitative care adding more mental stress to the caregiver (Dambi et al., 2014).

It is evidence that altered coping in the parent may have serious harmful effects on the child's psychosocial adjustment to living with a long-term disability (Duffy et al., 2011). In a study researcher used focus groups to examine the specific source of challenges as expressed by the parents themselves related to raising a child with a severe mental or physical disability, researcher revealed that, positive experiences of caregiving for a child with a severe disability, raising children with disabilities often have a greater appreciation for life, greater spirituality, increased compassion and tolerance for people with disabilities, a more united family, and overall greater mental and emotional strength (Resch et al., 2010).

Too much of responsibility can adversely affect the caregivers physical, psychological and social health (Brehout et al., 2009).To carry out any activity of daily living (ADLS) the cp child can impose all or partial load to the caregiver due to their activity limitation (Cramm, J. M., & Nieboer, A. P. 2011). During transfer and change in position by caregiver while lifting and carrying children might result in pain and strain of muscles (Davis et al., 2009).

In a previous study it is stated that while taking long term care of patient the caregiver naturally develop poor physical health and as the child's demands increase with age it will automatically affect the health, well-being and mental health of the parent or caregiver (Cramm, J. M., & Nieboer, A. P. 2011). Poor physical and emotional health is associated with child's behavior, short temperament of child and severity of child's disability (Brehaut et al., 2009). Mothers generally have to carry their children and the traditional method of carrying on the back utilized by the caregivers might give rise to increasing back pain (Dambi et al., 2015).

The transitional needs of caregivers, particularly mothers need more specific services, as their own social needs are often not met as they face challenges related to their child (Unsal-Delialioglu et ak., 2009). Much research suggests that there is a greater need of support for families during transitional times after a child is diagnosed with CP (Schuengel et al., 2009). In addition, a study done by Meleski, highlighted six additional areas of transitional need, initial diagnosis; when symptoms increase; when the child moves to a new setting such as a hospital; during a parent's absence, as in a divorce or military deployment, and during periods of developmental change (Vickers, M. H. 2014).

Regular and extensive care-giving has been shown to predispose caregivers to strain, stress, anxiety, depression and distress (Brehaut et al., 2009; Cheshire, Barlow & Powell 2010; Davis et al., 2009; Sawyer et al., 2011). The caregivers who developed high level of stress seem to have taken care of their child in most hours of the day and night (Murphy et al., 2007).The children having different disorder usually have the possibility of occurrence of psychological stress on carer and children having developmental delay have lower rate of well-being and high rate of emotional stress imposing caregivers perceives extreme burden (Estes et al., 2009). Mugno et al, reveal that caregivers of cerebral palsy child had been stressed, angry, tired and embarrassed due to their child's behavior (Yamada et al., 2012).

They felt like they had become more compassionate and more accepting to people with differences, some even mentioned that their child had influenced them to pursue healthcare careers and they mentioned that being able to rise to the occasion with a child with additional needs gave them a greater purpose in life, hence increasing their positive sense of taking care of a child with disabilities (Cramm, J. M., & Nieboer, A. P. 2011). Some cases still not known why some caregivers are able to cope caring their child and yet others do not will have suffered termed as burden (Chakravarti, 2008; Guillamón et al., 2013).

Depression is associated with the caregiver's perceived social supports, (Toly et al., 2012), who explored caregivers with children on ventilator assistance living in the home, and found that social support was a significant predictor of depression. Reduced or eliminated income due to providing care to the child; problems with the school system, medical establishment, and insurance companies; emotional distress, social isolation, stigma, and feeling of being completely overwhelmed (Brehaut et al., 2009; Resch et al., 2010).

Caregivers reported the most amount of burden from poor social interactions and stress caused by the medical community, insurance, school system, and social services. Overall picture of burden shows that many of the objective and subjective themes of burden were interrelated and respondent in one study reported that, stigma associated with their disabled child being in public or getting the interventions needed to sustain life using wheelchair, walking frame or any technical devices, this reveals the importance of the socio-cultural environment in the prevention of burden in the caregiver (Ton, C. D., 2012).

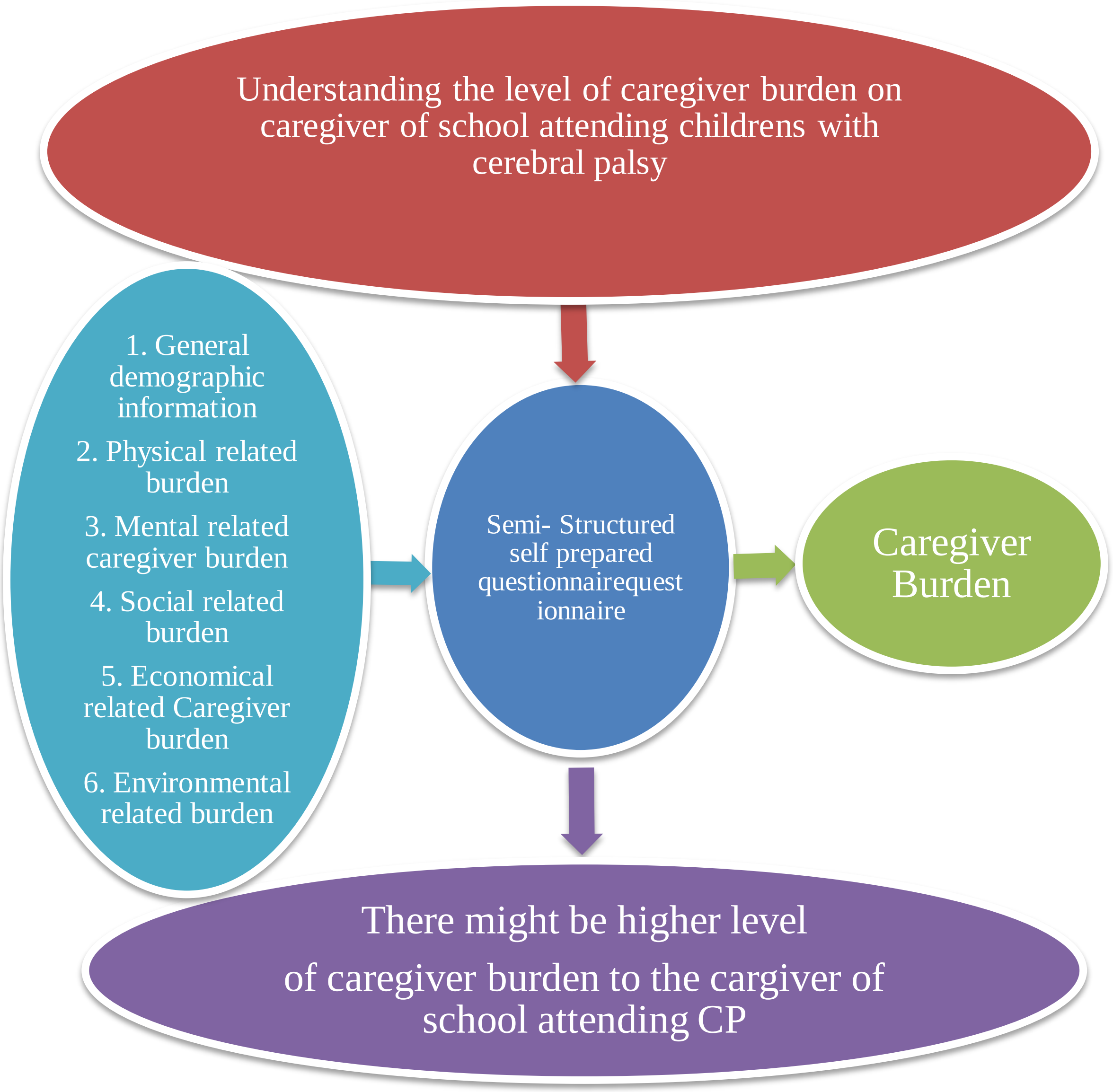
A statement of mother in a mixed method study done recently in Bangladesh about caregiver's burden shows how difficult and how much is the expressed and unexpressed loaded burden to a mother; "I do pottery at house all day long. I have to cook food for all at home three times a day. My father-in-law is ill; I have to take care of him. During sharecropping, when the crops arrive at our house, I have to work on that, have to look after my disabled child all the time. My husband sometimes helps me a bit in household work, but he does not help me with the child. He has no interest in the child. I feel stressed working so much at home. I never get the chance to relax at home. That's why I always feel weak. Now the child has grown up and she urinates and defecates lying down and sitting and it gets on her body. That's why I feel bad to clear her stool and urine" (Mother of a 9-year-old daughter), (Zuurmond et al., 2015). In 2010, approximately 65.7 million informal caregivers provided 80% - 90% of the long-term assistance in the home to children and adults with physical or cognitive limitations (Rosalyn Carter Institute for Caregiving, 2010).

While taking care of any child, time and money are important resources that are required and in case of disabled child the requirement of these resources are increased, many of the caregivers manage well with the increased additional demand of resources but those who failed to cope well usually lead towards depression, burden and stress (Brehaut et al., 2009). Care-giving leads to compromised working opportunities due to the conflicting demands of care-giving and employment thus ultimately resulting in limited opportunities to enter gainful employment (Brehaut et al., 2009; Davis et al., 2009).

Caregivers are likely to have lower educational attainment, have diminished opportunities of finding employment and subsequently are at high risk of financial crisis (Mu'ala, Rabati & Shwani 2008). The increase in financial burden with the passage of time can be accounted for by the recurrent usage of medical services (Davis et al., 2009). As CP is associated with diverse impairments (Aisen et al., 2011), children with CP often require routine medical attention leading to additional economic burden (Davis et al., 2009). On the other hand, according to Thompson and Gustafson if there is enough family income and balanced time management for care-giving, the factors of depression, stress and burden could be reduced (Glenn et al., 2009).

Environmental Prospective of caregiver burden is studied as contextual factors in previous studies but not as the independent factors that is studied to check associated factors. In current study, it tries to highlight the some of the association of environment causing for caregiver burden.

3.1. CONCEPTUAL FRAMEWORK



1. Fig: Conceptual frame work.

3.2. Research Objectives

3.2.1. General Objective

- To determine the level of caregiver burden of Children with Cerebral Palsy attending at William Marry Taylor school (WMTS).

3.2.2. Specific Objective

- To identify the caregiver`s general demographic information.
- To identify the physical related caregiver burden.
- To identify the mental related caregiver burden.
- To identify the social related caregiver burden.
- To identify the economical related caregiver burden.
- To identify the environmental related caregiver burden.
- To identify the association between level of caregiver burden and caregiver's demographic information (age, gender, occupation, primary caregiver, number of child, income, religion) of caregiver.
- To identify the association between level of caregiver burden and age of school attending Children having Cerebral Palsy.

3.3. Study Design

A descriptive cross-sectional study design was implied to conduct the research as this study aimed to evaluate the extent of caregiver burden of caregiver of school attending CP children in Bangladesh. As cross-sectional study this study examined the relationship between caregiver`s burden and other study variables such as Physical Domain, Mental Domain, Social Domain, Economical domain and Environmental Domain as they exist in a defined population. These main variables tried to find out the relative caregiver burden on the carer of school attending children.

3.4. Study Population

Information was collected from the informal primary caregiver of school attending CP child, especially mother and grandmother. Primary caregiver were supposed to have ability to answer to the question and discuss about the different burden they are facing while taking their disable child to school and bringing them back home in everyday basis. Primary care provider were interviewed about the physical related burden like caring or lifting the child for transfer or dragging wheel chair from home to school or vice versa. According to different literature review also it is evident that caregiver were exposed to mental related problem, so in this study also researcher tried to highlight the mental related burden. Writer also tried to find out the, economical, social and environmental related burden from the study population.

3.5. Study Site

Study site was William and Mary Taylor inclusive education school, located at centre of rehabilitation for paralyzed in Savar, Dhaka, Bangladesh.

This school is providing a comprehensive inclusive education for varieties of disable children like cerebral palsy, autism, durfism, developmental delay, spinabifida and with the normal children without disability. As this is the best example for attending both informal and formal caregivers of cp child, the place is also feasible to conduct the study.

3.6. Study Period

The research protocol was presented and accepted at the end session of first year of M. Sc in Rehabilitation Science. Research data collection was completed within 3 months from the month of December 2017 to February 2018 and total study period was from the selection of thesis title in 2017 until the completion binding as a book, which is approximately one and half year i.e. 2017-2018. As because of language barrier to the researcher, research data was collected in the feasible time of the volunteer, who are students of Bangladesh Health Professional Institute (BHPI) and few data, was also collected with the help of teacher at the school.

3.7. Sampling Technique

The sampling method was Convenience Sampling. It is the non-probability purposive sampling technique where in a proportion of the population is selected on the basis of its convenient accessibility.

3.8. Sample size

According to previous recent study, the estimated prevalence of cerebral palsy in Bangladesh is 3.7/1000 children (Khandaker, et al 2015).

Thus at 5% level of significance, value of reliability $Z\alpha^2 = (1.96)^2 = 3.8416$

Prevalence from the previous study = 3.7/1000

Which in percent, 3.7/1000×100 = 0.37.

Therefore p= 0.37.

We have, q = 1 – p, 1- 0.37 = 0.63.

d = tolerable error = 5%= 0.05, $(0.05)^2 = 0.0025$

Now, applying formula sample size (n),

$$n = \frac{(z \propto)^2\, PQ}{d^2}$$

$$= \frac{3.841 \times 0.37 \times 0.63}{0.0025}$$

$$= \frac{0.8953371}{0.0025}$$

= 358.13

= 358.

Hence the sample size n= 358.

As according to previous prevalence of cerebral palsy in Bangladesh calculated sample was 358, the study sample size was 54 respondents taking total number of targeted population at the research site.

3.9. Sample Selection Criteria

3.9.1 Inclusion Criteria

- Both male/female informal caregivers.
- Primary care giver of school attending children with cerebral palsy.
- Age of caregiver : 18 years -60 years (because these group of parents can be able to provide proper care to their children with long term disability)
- Age of children was 5-18 years.

3.9.2 Exclusion Criteria

- Formal caregiver of the CP children.
- Caregiver of the non- CP children.
- Caregiver who doesn’t want to participate in this study.
- Caregiver who couldn’t interpret questions that was asked during data collection.

3.10. Data Collection technique/tools

Outcome data was collected using the semi-structured self made questionnaire which consists of five domains:

1) Physical Domain- this domain try to find out the physical related caregiver burden.

2) Mental Domain – It will try to highlight the psychological related burden while caring the school attending cerebral palsy children.

3) Social Domain- This domain tried to find out the because of caregiving burden how is social participation.

4) Economical Domain- This domain give insight of effect of economy and how badly affecting the parents of the cerebral palsy children.

5) Environmental Domain- Carrying the baby on back of caregiver on muddy road and dragging the wheel chair of children from home to school and vice versa is not an easy task in regular bases.

So questionnaire was prepared considering the exact scenario and to highlight the problem through this study and try to minimize the caregiver burden in future.

Questionnaire was prepared by the researcher in English, and translation in bangle language was done by 3 friends' separately and comparison was done to make a final best questionnaire. Guidance from research supervisor was also taken and his positive feedback could make it final.

All questionnaires were both in English and Bengali language (with forward and backward translation).

3.11. Analysis

Editing

The collected data were checked for accuracy, completeness and utility

Coding

The responses were coded and recorded as per requirement after the data has been edited.

Tabulation

The coded data was tabulated in the master sheet.

Data presentation:

Data were categorized on the basis of research objectives than arranged, entered, and tabulated in computer to present the findings of the study. Demographic information like age, gender, occupation, family income in average, number of child of respondents and religion were presented on, bar graph, pie chart. Association between score of caregiver burden and different study variables are presented in table.

Data Analysis

Microsoft Office Excel and SPSS (Statistical Package for Social Science) version 16.0 were used for both descriptive and inferential statistics.

Statistical Analysis:

Descriptive statistics like percentage, frequency, mean, and standard deviation were used to present different result of the study.

3.12. Quality assurance

Questionnaire was to determine the level of caregiver burden of Children with Cerebral Palsy attending at William Marry Taylor school. To ensure and improve the quality of the study, first questionnaire was translated in the national language that is Bangla language following the standard procedure of linguistic validation.

For translation, two individual who were fluent in both languages were assigned for forward translation. They both prepare two versions of questionnaires then they both sat together and discussed and come up with one first version of translated questionnaire. Then this translated version was provided to another person who was fluent in both languages and who have not seen the original copy of questionnaire for backward translation. Then all three translators sat together and consensus was drawn with final version of translated questionnaires in Bangla language.

Then the pilot study had been conducted for the questionnaire to ensure the validity of the questionnaire. With the help of this survey, the unmet and required changes can be made and rearrange the questionnaire to make it easiest, understandable, and clear to the participants. The questionnaires filled by all those participants were kept safely in other to maintain confidentiality of participants. The data collected had been reviewed several times before entering into the SPSS program to reduce the errors that are likely to occur while entering and analysis of the collected data. The data were being re-coded in the required variables. Analysis of the data was done from the computer to minimize the errors.

3.13. Ethical Consideration

- Written consent was obtained from Institutional Review Board (IRB) of Bangladesh Health Professional Institute.
- Verbal and written consent was taken from all the participants before data collection to maintain their right to have information.
- Purpose of the data collection was explained to the participants.
- The vagueness and confidentiality of the subjects was maintained by keeping code number in questionnaire as well as after data collection.
- None of the participants was force to participate in the study.
- Information gathered was used only for research purpose.
- The world health organization and BMRC guidelines also followed to conduct the study.

CHAPTER-IV RESULT

Thesis data were collected from the primary care giver of cerebral palsy children attending at William and Mary Tailor School (WMTS) at CRP Savar, Dhaka, using the self prepared semi-structured care giver questionnaire for child. Collected data was analyzed to find the answer to research question or problem. In order to facilitate the interpretation, the data were presented in the tables and graphs. The gathered information was analyzed according to the research objective. Data were analyzed by using statistical package for social science (SPSS, version 16.0). The mean and standard deviation of the variables were also calculated.

Mean age of cp child was (μ-10.31) years with standard deviation of (SD ±2.718) which means these age group of children impose more burden as their weight are heavier to lift and transfer them. Likewise mean age of caregivers was 32.91 years and standard deviation (SD±6.094) suggestive of cp risk group mothers.

1. SOCIO-DEMOGRAPHIC INFORMATION

1.1 Age of primary caregiver

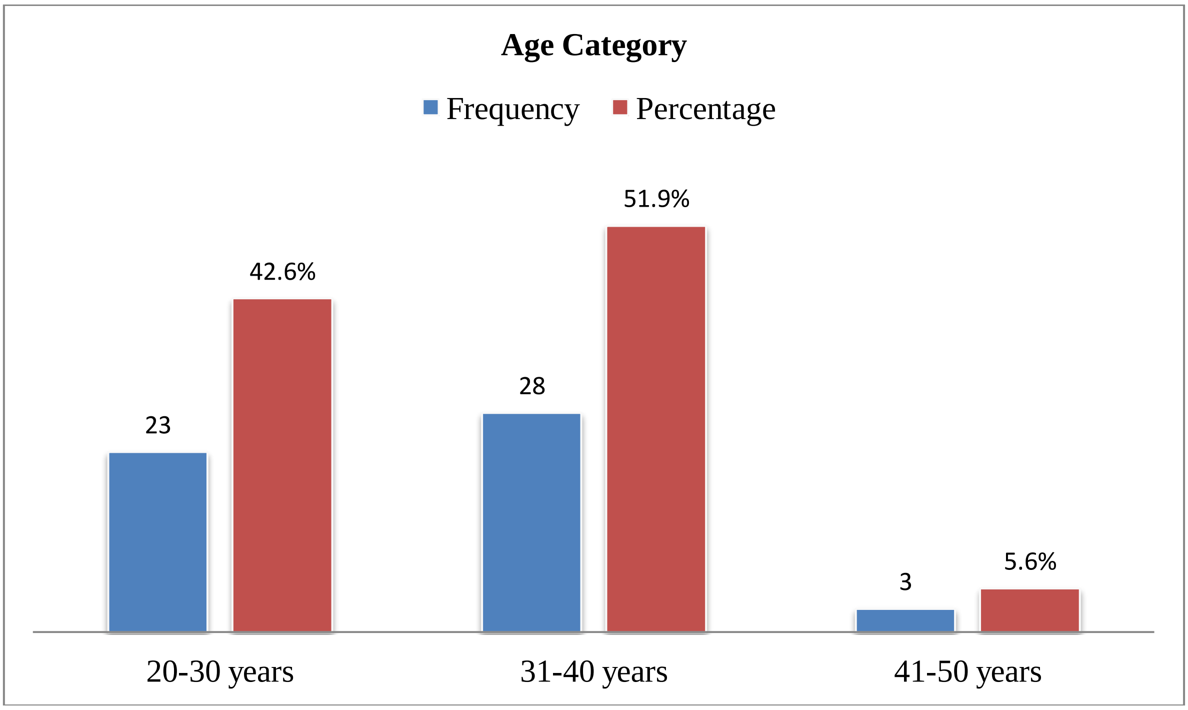


Fig I: Age category of primary caregiver

Age of caregiver was ranges from lowest twenty two (22) years to fifty (50) years old. Amongst the participants age mean age was (32.91) and standard deviation of age (6.094). In the age category of participants majority of caregiver mother were in the age group of (31-40) twenty eight participants (51.9%), which means medium age of participants have major number of their children born with cerebral palsy.

1.2. Age of Child

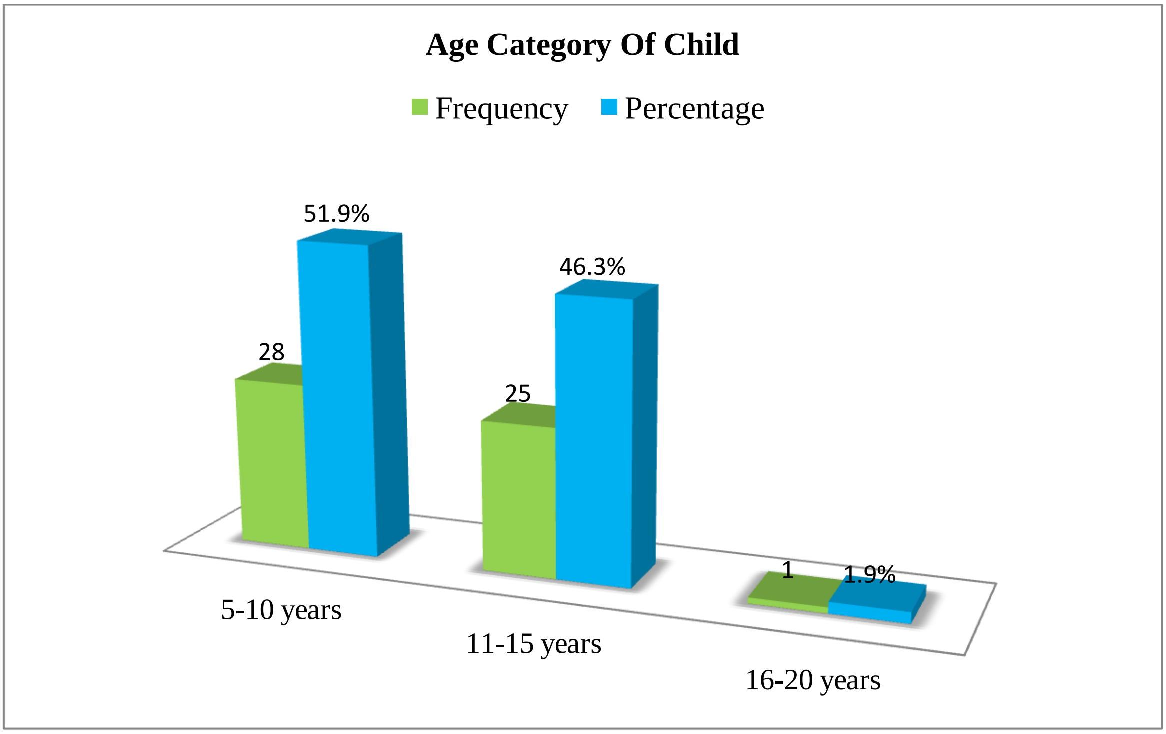


Fig II: Age Category of CP Child.

Age of children included in this study was from five (5) years old to seventeen (17) years old. According to age category (5-10) year's group twenty eight (28) had the highest number of participants and (16-20) age group had the lowest participant, which was only one (1) participant.

1.3. Gender of CP child

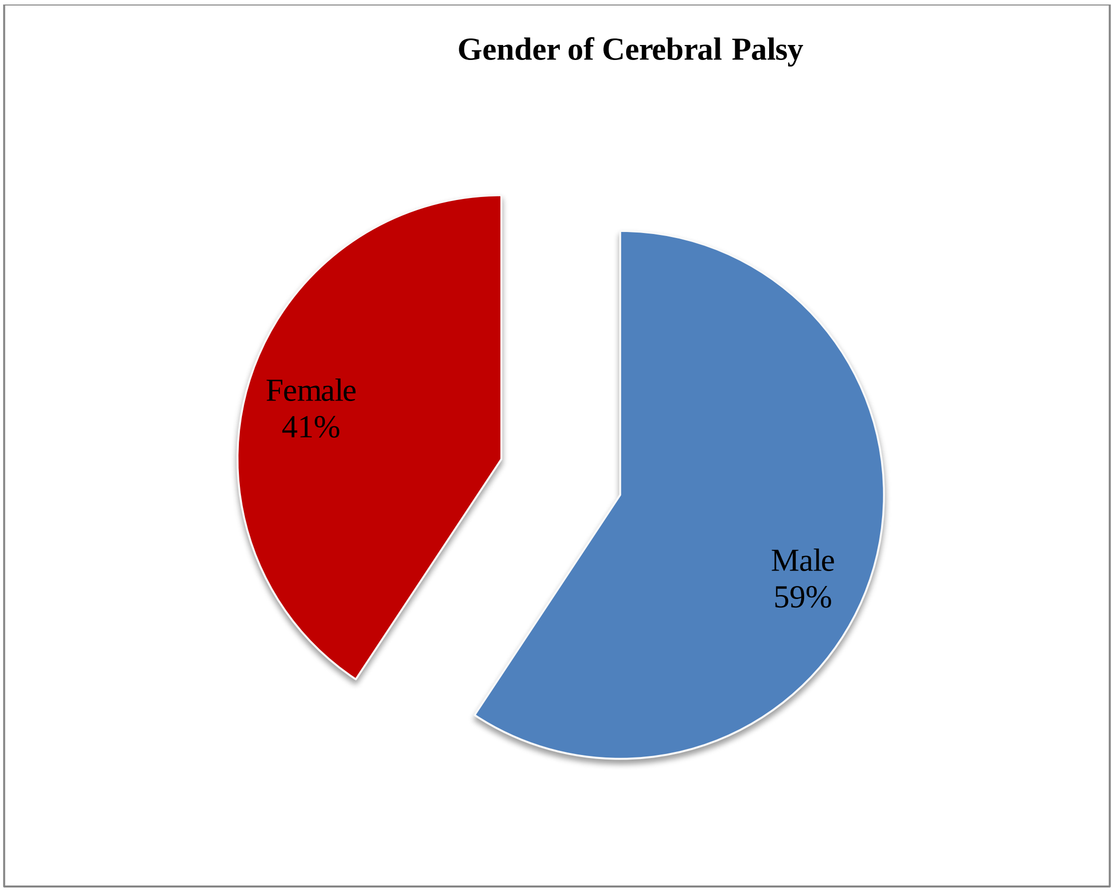


Fig III: Presentation of gender of CP child.

Gender of participants child was male dominant, which was thirty two (32)/(59.3%) male cp child and twenty two (22)/(40.7%) were female cp child, where as gender of caregiver was only female, common was mother fifty three (53)/(98.1%) and one was(1)/(1.9%) grandmother.

1.4 Primary Caregiver

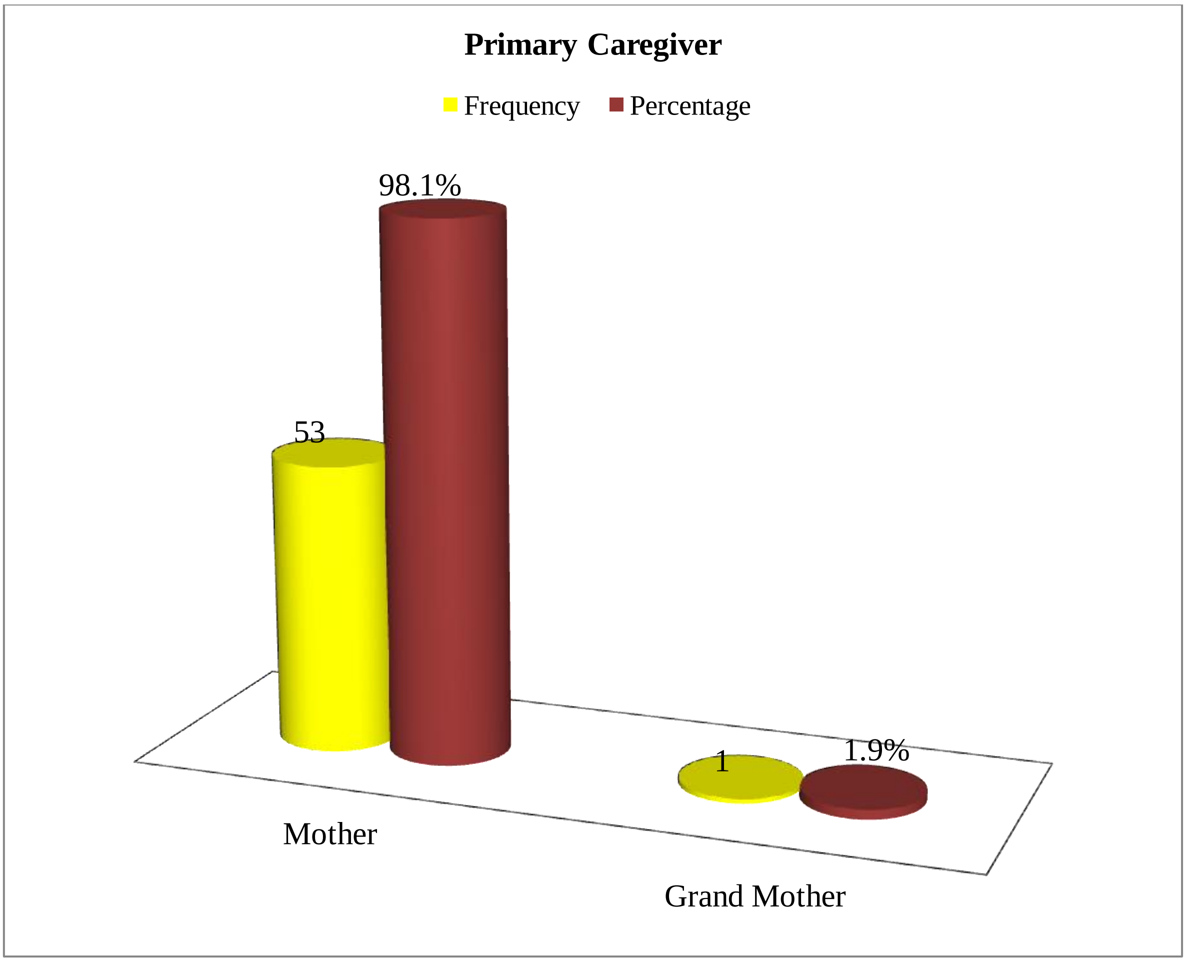


Fig IV: Primary Caregiver

In this study only female participants shows the primary caregiver, of them fifty three 53(98.1%) were mothers and only one 1(1.9%) grandmother.

1.5 Family Income

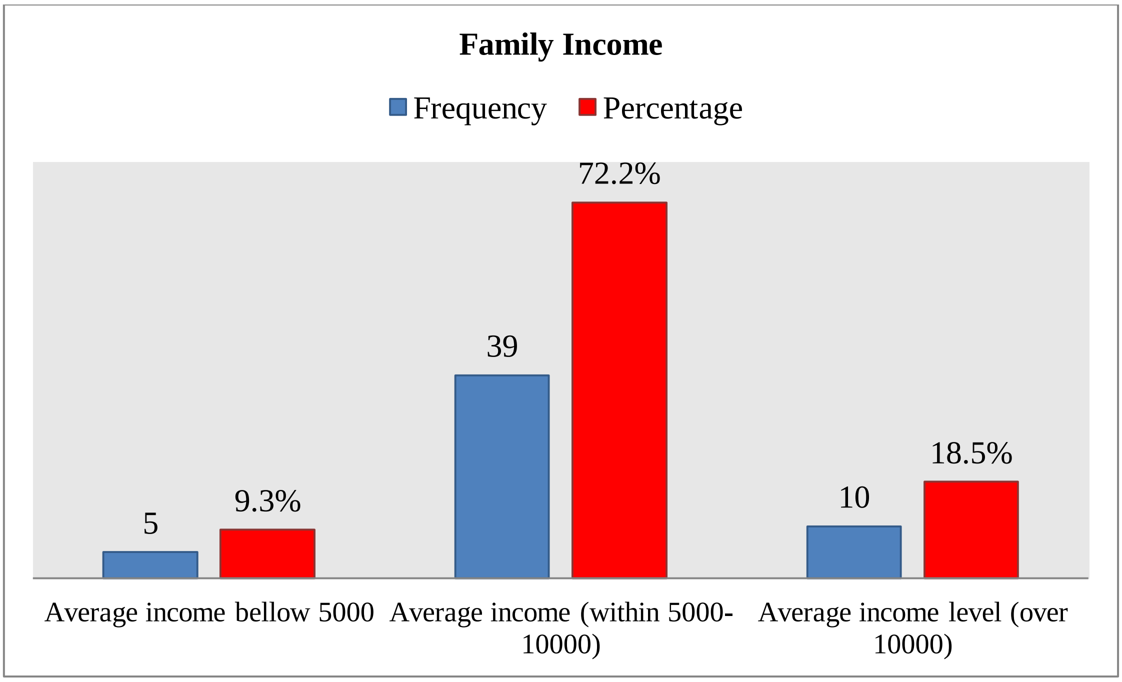


Fig V: Family Income

Family income value was taken from (Vocational Training Impact Study Questionnaire- CRP)

All the participants were asked about their family income in three categories as a) Average income bellow taka 5000. b) Average income (within taka 5000-10000). c) Average income level (over taka 10000). So from the result mean average level of income group are the majority of participants. From the study population mean level family income 39(72.2%) of categories were dominant and above mean level category have least caregiver burden 5(9.3%). Which indicating there is a still high economical related caregiver burden.

1.6 Number of Child

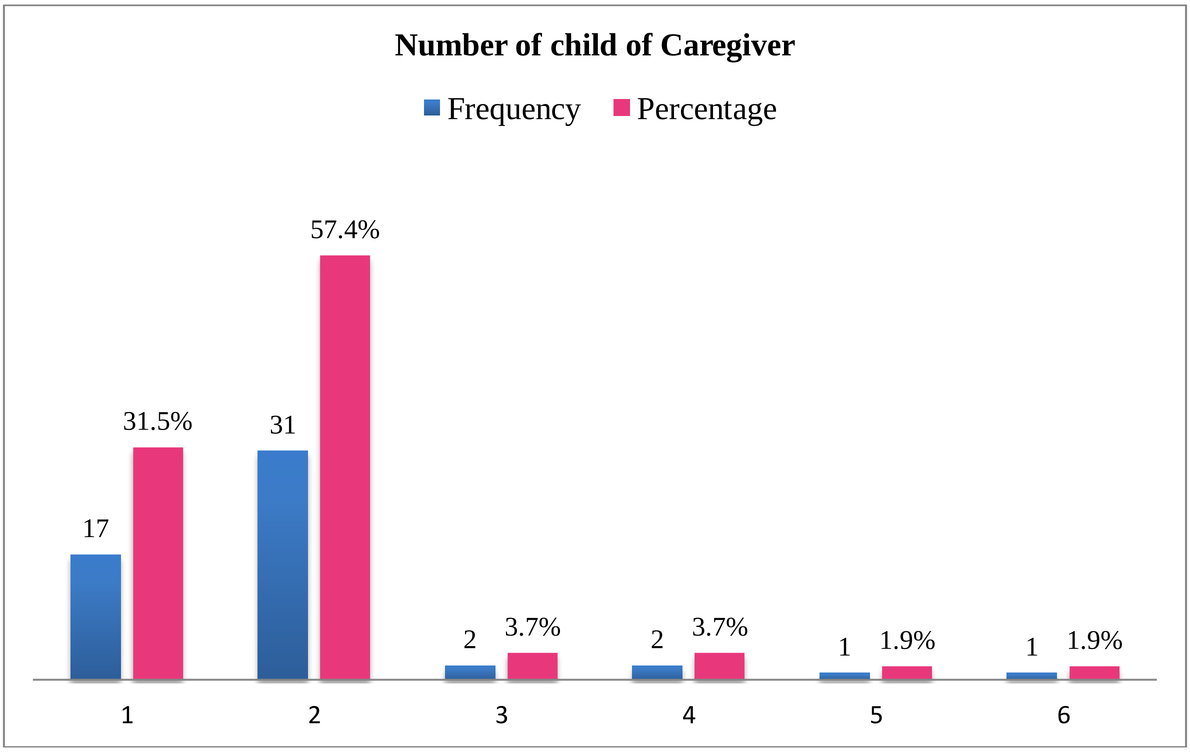


Fig VI: Number of Child

According to present study result, amongst 54 caregiver thirty one 31(57.4%) have two child, seventeen 17(31.5%) caregiver have one child, like wise two-two caregivers have three and four 3 and 4 child accordingly, in addition 1-1 parents have five and six child. This figure shows that most of the participants have 2 and 1 children and they even pose more caregiver burden.

1.7 Religion of caregiver

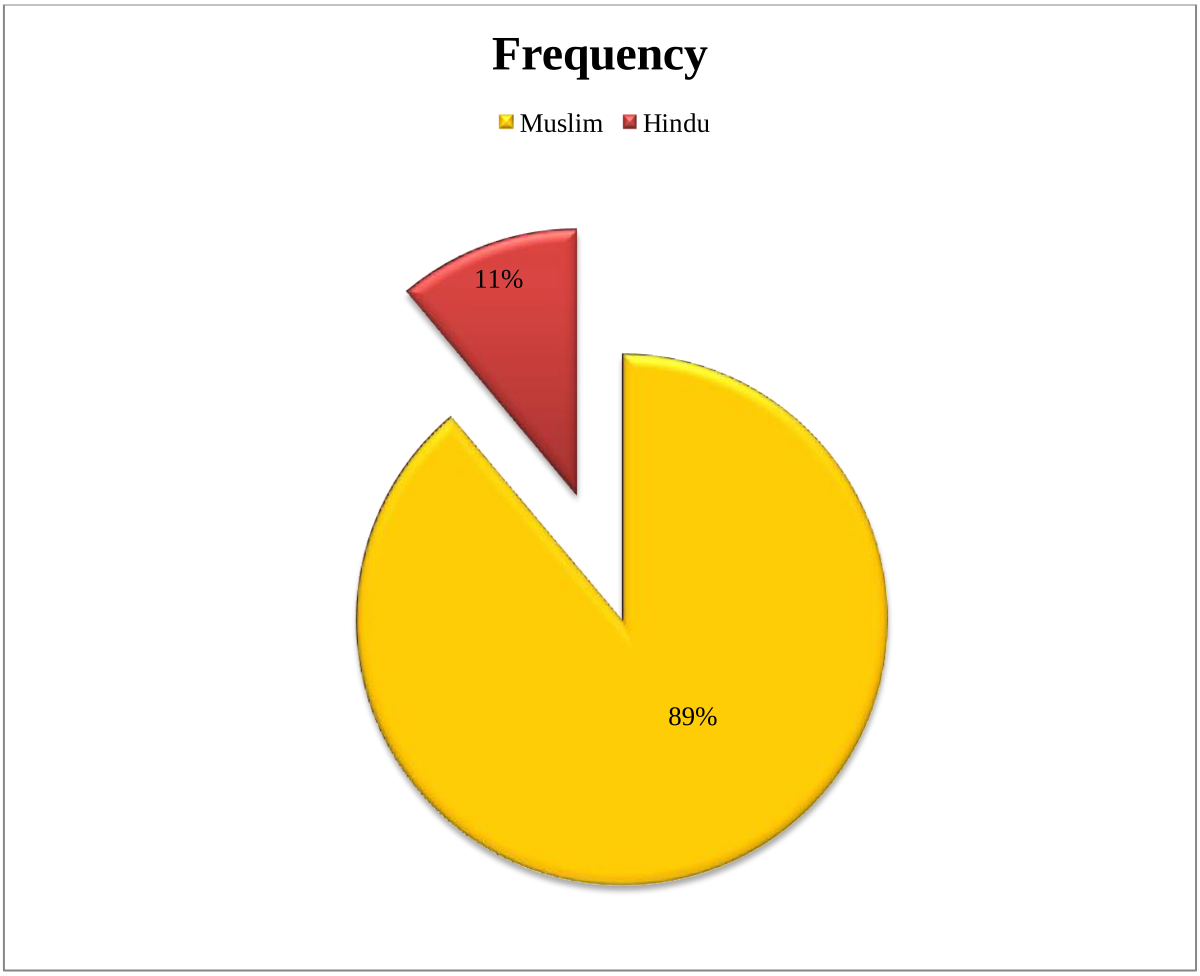


Fig VII: Religion Of caregiver.

From the 54 total participants forty eight 48(88.9%) were the Muslim mothers and rest of the six 6(11.1%) were from Hindu religion.

1.8 Score Category of CBSS

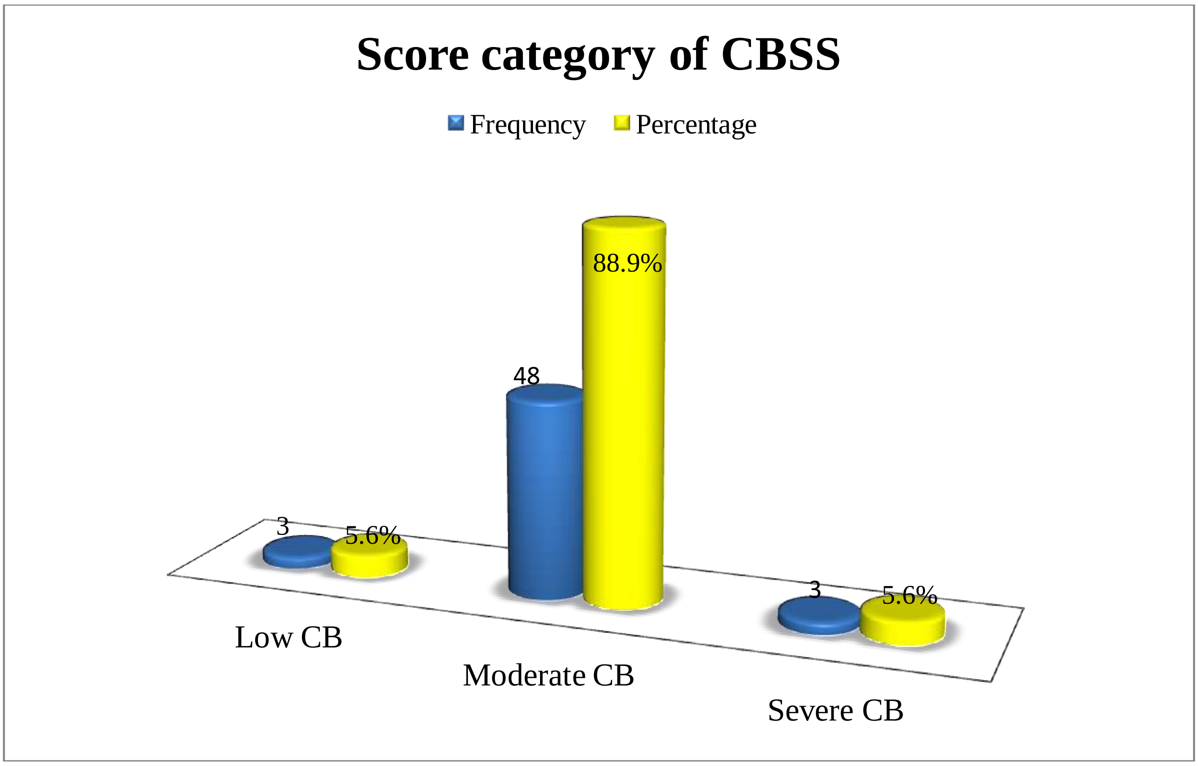


Fig VIII: Score Category

Score Interpretation: Low caregiver burden= 1-40 score, Moderate caregiver burden=41-80 and Severe caregiver burden= 80-100 score. Interpretation of caregiver burden shows, majority of participants have moderate caregiver burden, which was forty eight 48(88.9%), study shows that, low caregiver burden and severe caregiver categories have same level of burden. Mean score µ =2 and standard deviation of score SD= 0.336.

2. Table I: Association between Different study variables & CBSS.

Association between Different study variables and caregiver burden score scale

Variables	Statistics (χ^2)	(df)	*p*-value
Age of the child with cp	.831a	4	.934
Gender of child	.930a	2	.628
Primary caregiver of the cp child	.127a	2	.938
Age of primary caregiver	6.881a	4	.142
Religion of caregiver	3.375a	2	.185
Child & caregiver live with	1.727a	6	.943
Number of child	18.726a	10	.044
Family Income	1.884a	4	.757

χ^2, chi-square; df, degrees of freedom.

There was no relation between caregiver burden score scale (CBSS) and age of cp child, as p-value is 0.934 which is bigger than 0.05. Association between gender of child and CBSS was not met as p-value was 0.628 which is lesser than the 0.05. There was no relationship between primary caregiver and CBSS where p value is 0.938, which is above the set value 0.05, implies not significant. The association between caregiver burden score scale and age of primary caregiver, religious view of caregiver and living relation of child

& caregiver, was not satisfied as p value is 0.142, 0.185 and 0.943 respectively which is greater than 0.05.

The association was established between only with caregiver burden score scale and number of child, where p- value =0.044), which is less than 0.05 likely showing strong significant. Lastly the relationship between family income category and caregiver burden score category also shows non-significant as the p value is 0.757 which is more than the p-value 0.05.

2.1. Table II: Analysis of main study variables

Mean Score and Standard deviation of the different variables of the study

Study Variables	Mean Score	Standard deviation
Physical Domain	3.1157	1.15509
Mental Domain	2.9491	0.95337
Social Domain	2.9491	1.07981
Economic Domain	3.1944	0.76118
Environmental Domain	3.5278	0.67758

1. Physical related caregiver burden:

According to statistical analysis means score of physical domain was (3.1157) and standard deviation was (1.15509), which is less than half of the mean variable. This mean value shows that physical related caregiver burden was greater than mental and social related domain. Carrying child in their back in a typical eastern style in regular basis is physically challenging job.

2. Mental related caregiver burden:

Mean score of mental domain was (2.9491) which were more than half of the standard deviation (0.95337). In comparison with other four domains it is less then all of them and equal to social domain mean score, stating mental related caregiver burden is comparatively lower, this score might be lesser because caregivers were adapted with caregiving situation.

3. Social related caregiver burden:

Standard deviation of social domain was (1.07981) as a less than half of mean score (2.9491). The mean score obtained in social domain was equal to mental domain; in contrast with other three domains it is lesser. Social perception might have well adapted and tolerated by caregiver on social participation about the disability of their child. Despite of disability of their child parents might have adapted in new challenge and new situation.

4. Economic related caregiver burden

Mean score of economic domain was (3.1944) and standard deviation (0.76118). This score is second highest in overall domain, which states maximum caregiver has greater burden on caring their child due to economic status.

5. Environmental related caregiver burden

Achieved mean score of environmental domain was (3.5278) with standard deviation of the score (0.67758). Amongst all five domains environmental domain exerted highest level of caregiver burden. According to the participants while dragging the wheelchair of the child from home to school and vice versa was always a hard task with lots of physical challenge. Wheel chair propelling footpath or road is not even and it’s always crowded which exceeds the beyond of caregiving capacity of caregiver in regular schedule which ultimately leads to caregiver burden.

CHAPTER-V DISCUSSION

Opinion in gaining approach into the experiences of caregiving to school attending cerebral palsy children are not the typical old concept in western world, but its novelty for many countries in south East Asia and it is mandatory to see the caregiver burden on caregiver of school attending cp children. Identifying and categorizing burden perceived by caregivers of school attending cerebral palsy children is not that easy, as the caregivers are not only concerned with the needs of their disabled child, and as soon as they bring the child in school, almost immediately they return home to care other child and do their household work. As a primary caregiver mainly mothers and a grandmother was identified, and none of the participants was male caregiver this result was supported by latest study (Piran et al., 2017).

This study is focused on quantitative analysis of caregiver burden on different categories of study variables, with aim to highlight caregiving challenges on physical domain, mental domain, economical domain, social participation domain and environmental domain. In this study the mean caregiver burden score was 2 which is very close to the score obtained by other studies 1.98, and 2.1 (Piran et al., 2017; Kobos, E., & Imiela, J. 2015) respectively, as they have used different caregiver burden scale and in this study self prepared caregiver burden scale was administered.

According to the result of the research, mean score of physical domain was (µ:3.1157) and standard deviation (SD: 1.15509), which is third highest amongst all five study variable in the study. The score obtained in the domain tends to have ability to impose more burdens to caregiver. In general observation during the time of data collection and observation made at the time of they bring the child and take home by carrying many younger child in regular basis on typical style, lifting them and transferring them impose mild to severe back pain, leading in poor quality of life and negative care to child. Supportive of this study, mothers generally have to carry their children and the traditional method of carrying on the back utilized by the caregivers might give rise to increasing back pain (Dambi et al., 2015).

The age category of school attending child are from the age 5 years to 17 years with mean age (µ-10.31) years and standard deviation (sd ±2.718) of the school attending cp child, some child can walk with minimal to maximal support, other may need to be carried by the caregiver on their waist or back in classical style along with the school bag and tiffin of the child so in regular basis it loaded extreme caregiver burden causing fatigue and back pain. Davis et al emphasizes on their study that, lifting and carrying children on regular basis on their back might result in overloaded physical pain (Davis et al. 2009).

In the current study most of the caregiver expressed the moderate level of anxiety and depressive behavior in long term care of their disabled child. There is significant variation in how parents adapt to the caregiving demand, various parents adapt well to the challenges of caring for a child with a disability, while others fail. The caregivers who were responsible for caregiving for a longer period, along with schooling cerebral palsy children, experienced lower caregiving burden in mental domain and social domain mean score (2.9491) equally. It seems that caregiver have accepted their child as just how they are and found point of adaptation to coping with their responsibilities. Unlike findings of this study, there is evidence indicating that as the length of disease increases, the caregiving burden and stress increases and reduced their quality of life (Nagaraju, K., &

Wilson, J. 2013). In contradiction of this study many study had concluded that long-term care-giving has been shown to predispose caregivers to strain, stress, anxiety, depression and distress, which is of chronic duration relative to the rest of the population (Brehaut et al. 2009; Cheshire, Barlow & Powell 2010; Davis et al. 2009; Sawyer et al. 2011).

Some previous studies presented contradictory results, they suggested that family structure affects the perception of caregivers of their health status, and caregivers in nuclear families have good quality of life with their health status than extended families, and experience lower emotional stress (Hsieh et al., 2009). Evidence suggest that, the social support provided by extended families decreases caregivers' responsibilities and stresses, and affects the health impacts of caregiver (Hsieh et al., 2009; Nagaraju, K., & Wilson, J. 2013;).

According to this study, moderate caregiver burden in this study may be the birth of other healthy children may decrease the dissatisfaction of caregivers because their responsibilities on other children increase their social interactions, and another reason could be their first and second or elder children being healthy they can help at household raring the child, therefore, diminish their caregiving burden and shows moderate mean score.

In the study according to participants, caregiver have to provide regular care at home in all needful activities of daily living. In addition they have to prepare for the school, bring them crossing the hurdles in roads, sometime excessive heat, most of the time it's the raining outside. Transportation is huge problem as it's difficult to put on rickshaw in regular basis, many child are wheelchair bounded so dragging wheel chair is not an easy tasks in everyday schedule and some child are younger so need to be carried on their back.

After they left the children in school they have to go home and do household activities as mainly mothers are involved in this study.

Despite of their entire very busy schedule just caring the disable child and household work it's very hard to take social participation. Many times caregivers found isolated just caring them, in favor of identification of this study, the social isolation increases in the caregivers of younger children, the caregivers of younger children experience higher caregiving burden in social isolation and disappointment bearing more stress (Kobos, E., & Imiela, J. 2015). Younger children need continuous support, the higher dependency of them on parent causes caregivers to spend more time for caregiving activities, and schooling them is very tough job, which restricts their social activities and makes it impossible for them to achieve their goals in life (Piran et al., 2017).

However, the extent of anxiety or depression resulting from caring for a child with CP is difficult to compute because of procedural flaws in designs of the studies, which have explored the issue of burden in regards with caring school attending cp child (Dambi et al., 2015).

A study reveal that the caregivers of children with cerebral palsy bear severe financial loads and face several problems including interruption and disturbance in family interactions and leisure time activities, so that their routine activities are affected by caregiving affairs (Piran et al., 2017). All the participants in this study were professionally not engaged and they were only housewife, in support of this study 70% reported that they could not work because they wanted to provide care for their disable children, approximately 20% of caregivers reported a total loss of income due to the child's needs and care, and 50% reported a reduced amount of time they could work due to the child's conditions, All these findings significantly shows that burden among these caregivers places a family at a financial disadvantage in compare to families with typically developing children (Ton, C. D. 2012)**.**

In the current study economical burden seems to be very high as mean score amongst all domains was in second highest position (µ-3.1944), which indicating further loaded burden to the caregiver. As economy plays the vital role running a smooth family but in addition family having long term disable person in the family demands extra and regular expenses. Different study also supported the finding of this study, as the increase in financial burden with the passage of time can be accounted for by the recurrent usage of medical services (Davis et al., 2010) which further input to the costs of raising a child with a disability, as CP is associated with various impairments (Aisen et al., 2011), children with CP often require routine medical attention (Davis et al. 2010) and this may overburden limited financial budgets. The study of Khana et al. showed that the caregivers of children with cerebral palsy bear severe financial loads and face several problems including interruption and disturbance in family interactions and leisure time activities, so that their routine activities are affected by caregiving affairs (Piran et al., 2017).

Furthermore, identification from this study about caregiving burdens, which were related to other studies were reduced or eliminated income due to providing care to the child; problems with the school system, medical establishment, and emotional distress, social isolation, stigma, and feeling of being completely overwhelmed (Brehaut et al., 2009; Resch et al., 2010). The respondents of this study indicated that financial burden mainly emerged when they were they don’t have job due to the amount of time that they were required to spend with their child regularly (Bourke-Taylor et al., 2010).

The analysis of study shows highest number of caregiver burden was found in the environmental domain of mean score 3.5278, this reflects the strong challenges to caregivers as the cerebral palsy child and parents stays far away from the school and they have to push and pull (propel) wheel chair, as the path and roads are not smooth. In Bangladesh rainfall is very common and water collection on the road and pathways which put further challenges. Although this study was quantitative, researcher also asked about the challenges they faced while bringing the child to school and taking back home, their expression and description about the situation was pathetic. Environmental domain that challenges in transportation of child added caregiver burden on school attending cerebral palsy children (Ton and C. D. 2012).

Limitation of the study

This study was carried out at only one inclusive school with total sample of n=54 participants. It would have better outcome with verities of environmental setting with greater number of participants which was the limitation of this study. As a researcher of the current study, I can assume that caregiver might give open and elaborative view about caregiver burden on their school attending cerebral palsy children, if qualitative study would have conducted.

CHAPTER- VI CONCLUSION & RECOMENDATION

6.1. CONCLUSION

Caregivers of children with cerebral palsy are affected with direct or indirect self-perception, social support, different stress and family functioning. This study concluded that caregivers are severely affected on coping with environmental situation while transferring cp child to school. Economical condition plays a vital role to perceive more caregiver burden as this study result shows majority of caregiver have average or mean level income but the mean level was found in 2nd top level among five study variables. Despite the strengths of this study, it exhibits some limitations.

As the study on caregivers burden on school attending cerebral palsy children was conducted for the first time in Bangladesh, however many study available only on caregiver burden on cerebral palsy children. This study tried to find out the extra loaded burden on caregiver within different study variables. However, very less study was found on environmental domain that imposes huge burden on caregiver while transferring their disabled child from home to school and vice versa and other important variable was physical burden and economical burden.

6.2. RECOMMENDATION

To overcome the main problem, there needs further study on environmental domain that affecting to parents while transferring their disable child to school. Some kind of financial grant to poor people and insurance related health and education to cerebral palsy children in South East Asia would be a great turning positive point for carer and sizable children.

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ANNEXES-I **INFORMED CONSENT**

Title: Understanding the level of caregiver burden on caregiver of school attending cerebral palsy children at William and Marie Taylor School CRP-Bangladesh

I am Rajan Tamang, student of M Sc. in Rehabilitation Science under Dhaka University, request you to participate in the research study for above mentioned research. The aim of the study is to find out the caregiver burden especially in the carer of school attending cerebral palsy children. Your participation in this study is voluntary. If you do not agree to participate at all you can withdraw your support to the study anytime you want, despite consenting to take part earlier. You will not be paid for your participation. The research will be directly beneficial for you as it deals with acknowledging the problems faced by you. This study will not the cause any risk or harm to you. Confidentiality of all documents will be highly maintained. Collected data will never be used in such a way that you 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 anticipate.

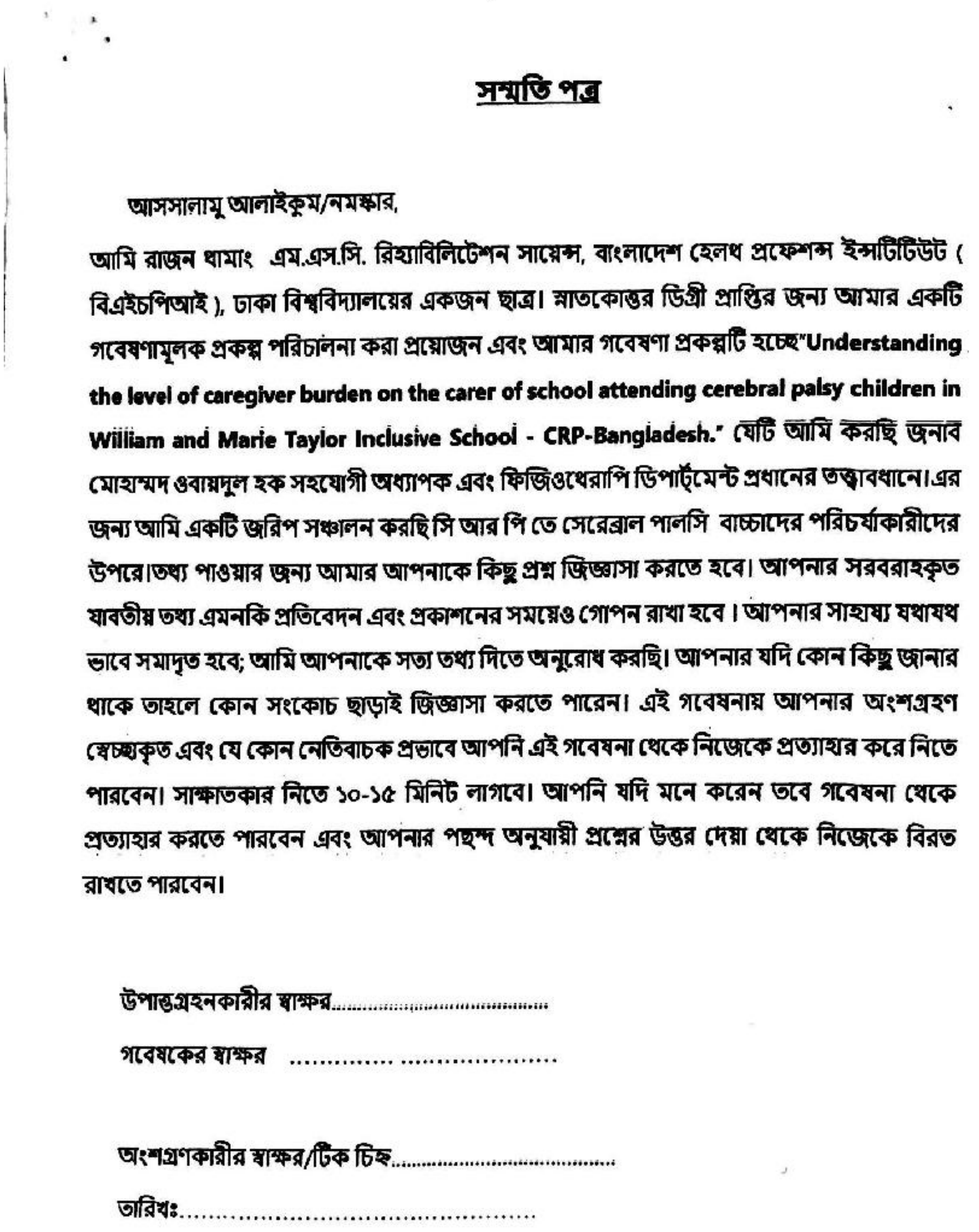
I have read or have been explained to me the information sheet and I am informed about the topic of the research. I have got opportunity to ask any query and discuss about the study. I have been asked have been answered to my satisfaction. I consent voluntarily to be a participant in this study.

Name of Participant: ……………………

Signature of Participant: ……………….

Date: …………………………………

ANNEXES- I.I **CONSENT**



সম্মতি পত্র

আসসালামু আলাইকুম/নমস্কার,

আমি রাজন থামাং এম.এস.সি. রিহ্যাবিলিটেশন সায়েন্স, বাংলাদেশ হেলথ প্রফেশন্স ইন্সটিটিউট (বিএইচপিআই), ঢাকা বিশ্ববিদ্যালয়ের একজন ছাত্র। স্নাতকোত্তর ডিগ্রী প্রাপ্তির জন্য আমার একটি গবেষণামূলক প্রকল্প পরিচালনা করা প্রয়োজন এবং আমার গবেষণা প্রকল্পটি হচ্ছে"**Understanding the level of caregiver burden on the carer of school attending cerebral palsy children in William and Marie Taylor Inclusive School - CRP-Bangladesh.**" যেটি আমি করছি জনাব মোহাম্মদ ওবায়দুল হক সহযোগী অধ্যাপক এবং ফিজিওথেরাপি ডিপার্টমেন্ট প্রধানের তত্ত্বাবধানে।এর জন্য আমি একটি জরিপ সঞ্চালন করছি সি আর পি তে সেরেব্রাল পালসি বাচ্চাদের পরিচর্যাকারীদের উপরে।তথ্য পাওয়ার জন্য আমার আপনাকে কিছু প্রশ্ন জিজ্ঞাসা করতে হবে। আপনার সরবরাহকৃত যাবতীয় তথ্য এমনকি প্রতিবেদন এবং প্রকাশনের সময়েও গোপন রাখা হবে । আপনার সাহায্য যথাযথ ভাবে সমাদৃত হবে; আমি আপনাকে সত্য তথ্য দিতে অনুরোধ করছি। আপনার যদি কোন কিছু জানার থাকে তাহলে কোন সংকোচ ছাড়াই জিজ্ঞাসা করতে পারেন। এই গবেষনায় আপনার অংশগ্রহণ স্বেচ্ছাকৃত এবং যে কোন নেতিবাচক প্রভাবে আপনি এই গবেষনা থেকে নিজেকে প্রত্যাহার করে নিতে পারবেন। সাক্ষাতকার নিতে ১০-১৫ মিনিট লাগবে। আপনি যদি মনে করেন তবে গবেষনা থেকে প্রত্যাহার করতে পারবেন এবং আপনার পছন্দ অনুযায়ী প্রশ্নের উত্তর দেয়া থেকে নিজেকে বিরত রাখতে পারবেন।

উপাত্তগ্রহনকারীর স্বাক্ষর...................................

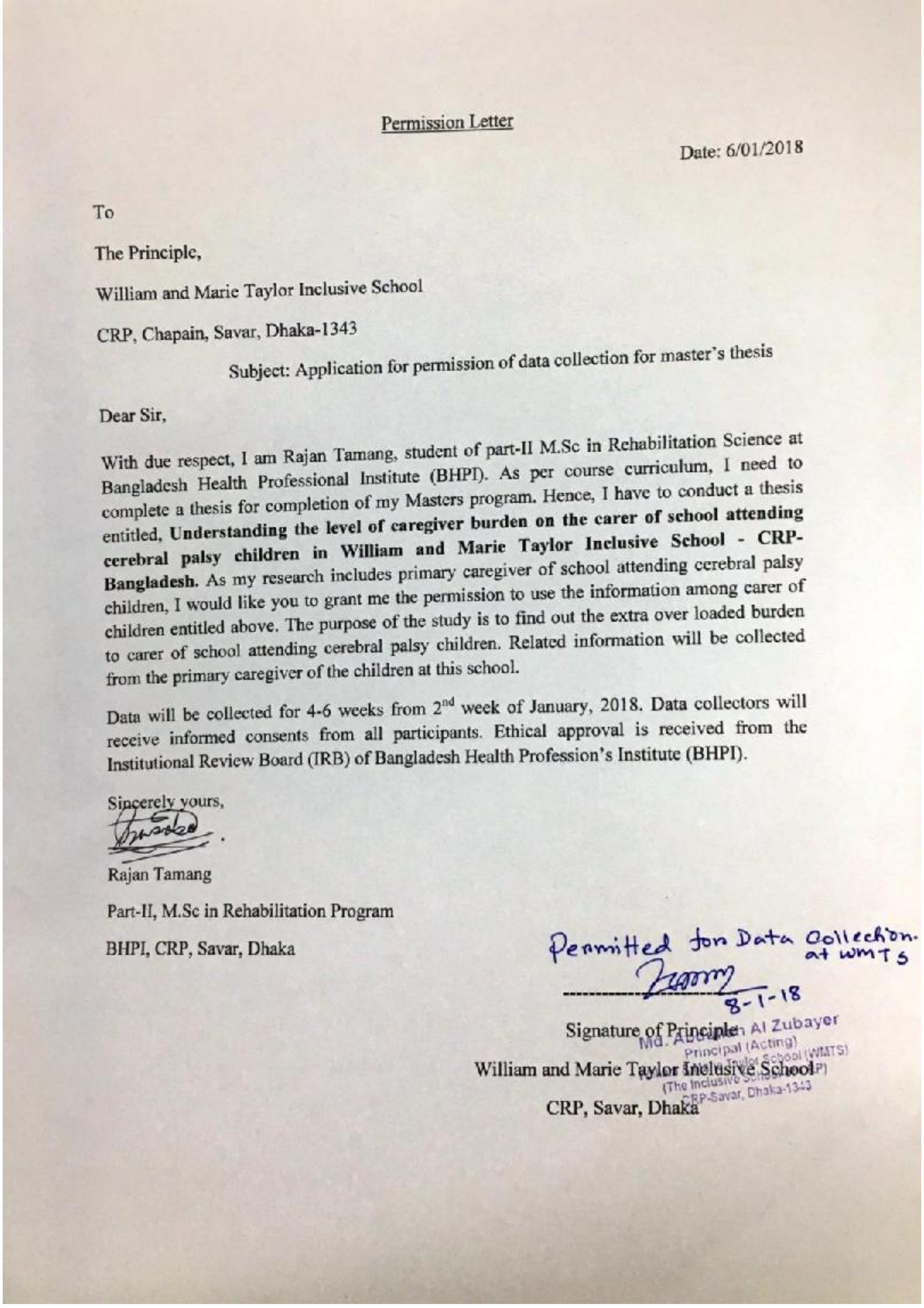
গবেষকের স্বাক্ষর ....

অংশগ্রণকারীর স্বাক্ষর/টিক চিহ্ন.......................................

তারিখঃ...

ANNEXES-II **PERMISSION FROM IRB**

PERMISSION LETTER FROM INSTITUTION REVIEW BOARD (IRB)



Permission Letter

Date: 6/01/2018

To

The Principle,

William and Marie Taylor Inclusive School

CRP, Chapain, Savar, Dhaka-1343

Subject: Application for permission of data collection for master's thesis

Dear Sir,

With due respect, I am Rajan Tamang, student of part-II M.Sc in Rehabilitation Science at Bangladesh Health Professional Institute (BHPI). As per course curriculum, I need to complete a thesis for completion of my Masters program. Hence, I have to conduct a thesis entitled, **Understanding the level of caregiver burden on the carer of school attending cerebral palsy children in William and Marie Taylor Inclusive School - CRP-Bangladesh.** As my research includes primary caregiver of school attending cerebral palsy children, I would like you to grant me the permission to use the information among carer of children entitled above. The purpose of the study is to find out the extra over loaded burden to carer of school attending cerebral palsy children. Related information will be collected from the primary caregiver of the children at this school.

Data will be collected for 4-6 weeks from 2nd week of January, 2018. Data collectors will receive informed consents from all participants. Ethical approval is received from the Institutional Review Board (IRB) of Bangladesh Health Profession's Institute (BHPI).

Sincerely yours,

Rajan Tamang

Part-II, M.Sc in Rehabilitation Program

BHPI, CRP, Savar, Dhaka

Permitted for Data Collection.
at WMTS

8-1-18

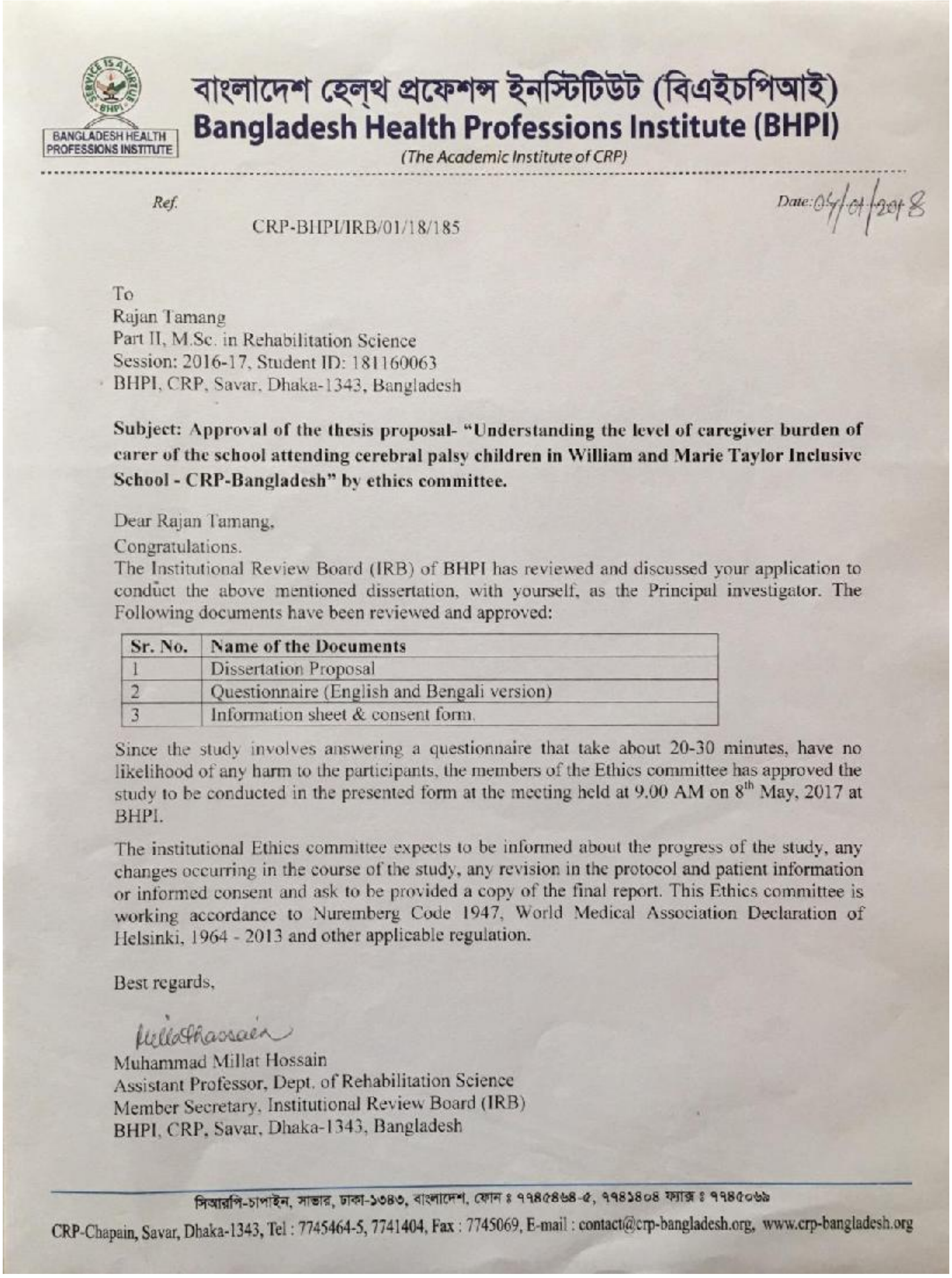
Signature of Principle

William and Marie Taylor Inclusive School

CRP, Savar, Dhaka

Md. Abd[illegible]n Al Zubayer
Principal (Acting)
[illegible] Taylor School (WMTS)
(The Inclusive [illegible]P)
CRP-Savar, Dhaka-1343

PERMISSION LETTER FROM THE RESEARCH SITE



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

Ref. CRP-BHPI/IRB/01/18/185

Date: 04/01/2018

To
Rajan Tamang
Part II, M.Sc. in Rehabilitation Science
Session: 2016-17, Student ID: 181160063
BHPI, CRP, Savar, Dhaka-1343, Bangladesh

Subject: Approval of the thesis proposal- "Understanding the level of caregiver burden of carer of the school attending cerebral palsy children in William and Marie Taylor Inclusive School - CRP-Bangladesh" by ethics committee.

Dear Rajan Tamang,

Congratulations.

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

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

Since the study involves answering a questionnaire that take about 20-30 minutes, have no likelihood of any harm to the participants, the members of the Ethics committee has approved the study to be conducted in the presented form at the meeting held at 9.00 AM on 8th May, 2017 at BHPI.

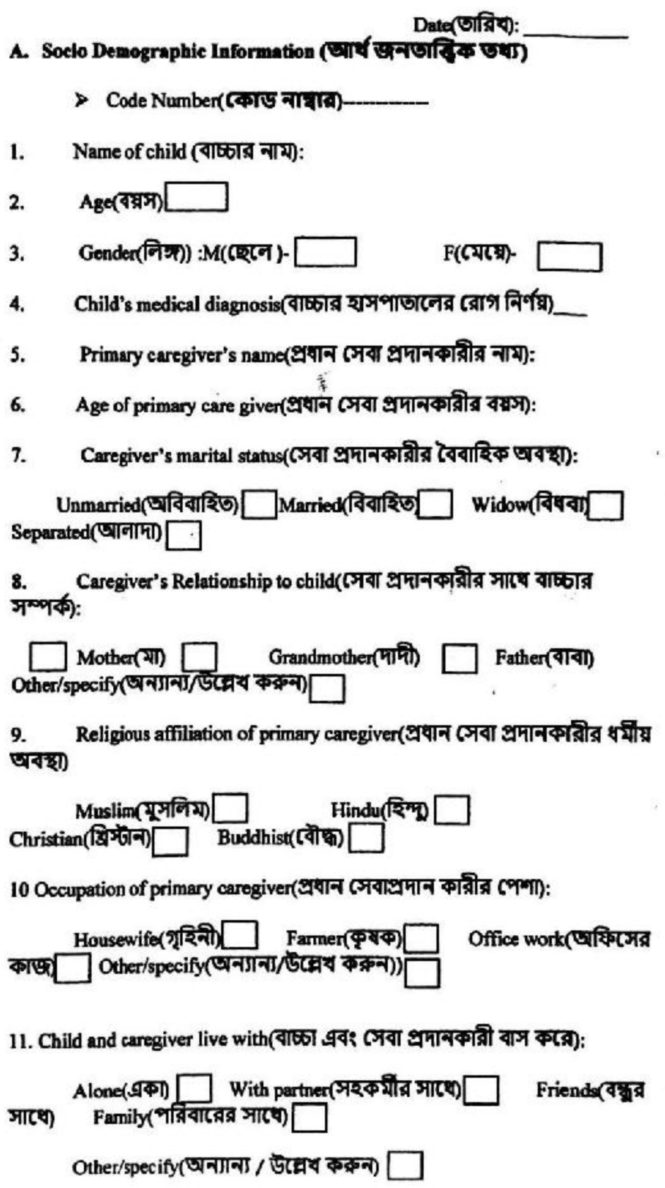
The institutional Ethics committee expects to be informed about the progress of the study, any changes occurring in the course of the study, any revision in the protocol and patient information or informed consent and ask to be provided a copy of the final report. This Ethics committee is working accordance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

Best regards,

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

সিআরপি-চাপাইন, সাভার, ঢাকা-১৩৪৩, বাংলাদেশ, ফোন ঃ ৭৭৪৫৪৬৪-৫, ৭৭৪১৪০৪ ফ্যাক্স ঃ ৭৭৪৫০৬৯
CRP-Chapain, Savar, Dhaka-1343, Tel : 7745464-5, 7741404, Fax : 7745069, E-mail : contact@crp-bangladesh.org, www.crp-bangladesh.org

ANNEXES- IV QUESTIONNAIRE (English & Bangla)



Date(তারিখ): ____________

A. Socio Demographic Information (আর্থ জনতাত্ত্বিক তথ্য)

- Code Number(কোড নাম্বার)------------

1. Name of child (বাচ্চার নাম):

2. Age(বয়স) ☐

3. Gender(লিঙ্গ)) :M(ছেলে)- ☐ F(মেয়ে)- ☐

4. Child's medical diagnosis(বাচ্চার হাসপাতালের রোগ নির্ণয়)___

5. Primary caregiver's name(প্রধান সেবা প্রদানকারীর নাম):

6. Age of primary care giver(প্রধান সেবা প্রদানকারীর বয়স):

7. Caregiver's marital status(সেবা প্রদানকারীর বৈবাহিক অবস্থা):

Unmarried(অবিবাহিত) ☐ Married(বিবাহিত) ☐ Widow(বিধবা) ☐ Separated(আলাদা) ☐

8. Caregiver's Relationship to child(সেবা প্রদানকারীর সাথে বাচ্চার সম্পর্ক):

☐ Mother(মা) ☐ Grandmother(দাদী) ☐ Father(বাবা) Other/specify(অন্যান্য/উল্লেখ করুন) ☐

9. Religious affiliation of primary caregiver(প্রধান সেবা প্রদানকারীর ধর্মীয় অবস্থা)

Muslim(মুসলিম) ☐ Hindu(হিন্দু) ☐ Christian(খ্রিস্টান) ☐ Buddhist(বৌদ্ধ) ☐

10 Occupation of primary caregiver(প্রধান সেবাপ্রদান কারীর পেশা):

Housewife(গৃহিনী) ☐ Farmer(কৃষক) ☐ Office work(অফিসের কাজ) ☐ Other/specify(অন্যান্য/উল্লেখ করুন)) ☐

11. Child and caregiver live with(বাচ্চা এবং সেবা প্রদানকারী বাস করে):

Alone(একা) ☐ With partner(সহকর্মীর সাথে) ☐ Friends(বন্ধুর সাথে) Family(পরিবারের সাথে) ☐

Other/specify(অন্যান্য / উল্লেখ করুন) ☐

12. Number of children in the family(পরিবারে বাচ্চার সংখ্যা): ☐ ☐

13. Family Income(পরিবারের আয়):

☐ গড় আয়ের উপরে ☐ গড় আয় ☐ গড় আয়ের নিচে

Participant`s Name(অংশ গ্রহনকারীর নাম) ____________________

Interviewer`s Name(সাক্ষাতকারীর নাম):____________________

Questionnaire(প্রশ্নাবলী)

	Never কখনোই না [1]	Almost Never প্রায়শ না [2]	Some-times মাঝে মাঝে [3]	Fairy often হয় তবে কম [4]	Very Often প্রায়শই হয় [5]
Physical Domain(শারীরিক ক্ষেত্র) 1.How often have you felt pain because of carrying the child to school and taking back to home?(বাচ্চাকে স্কুলে নিয়ে যেতে এবং বাসায় বহন করে নিয়ে আনার জন্য কখনো আপনি কষ্টবোধ করেছেন?)					
2. How often have you felt that feeding in the school was not your responsibility, because it is extra burden to you and you do regularly at home/hostel?(আপনার কখনো অনুভূত হয়েছে যে স্কুলে বাচ্চাকে খাওয়ানো আপনার দায়িত্ত নয়,কারণ এটা আপনার উপর অতিরিক্ত বোঝা এবং আপনি এই কাজটা নিয়মিত বাসায়/হোস্টেলে করেন?)					
3.How often have you felt that you are taking a big burden to schooling the children because it takes lots of physical effort? (আপনার কখনো অনুভূত হয়েছে যে আপনি বাচ্চাকে স্কুলে নিয়ে যাবার					

ক্ষেত্রে বড় বোঝা নিচ্ছেন কারণ এতে প্রচুর শারীরিক শ্রমের প্রয়োজন হয়?)					
4. How often have you felt very tired of carrying the child?(বাচ্চাকে বহন করতে গিয়ে কখনো নিজেকে খুব ক্লান্ত মনে হয়েছে?)					
Mental Domain(মানসিক ক্ষেত্র) 5. How often have felt Mentally upset for caring this Child?(আপনি কখনও মানসিক ভাবে বিপর্যস্থ অনুভব করেছেন কারণ শুধুমাত্র আপনাকে বাচ্চার প্রতি যত্ন নিতে হয় তাই?)					
6. How often have you felt shy because you have to propel wheel chair or carry/drag the child to school? (আপনি কখনও লজ্জিত বোধ করেছেন কারণ আপনাকে হুইলচেয়ার চালাতে হয় অথবা বহন/টানতে হয় বাচ্চাকে স্কুলে আনতে?)					
7. How often have you became angered because the child did not obeyed as you wanted to do him/her?(আপনি কখনও খুব রাগান্বিত হয়েছেন কারণ আপনি বাচ্চার থেকে যা চান,সে তা ঠিকভাবে মেনে চলতে পারে না?)					
8.How often have you felt very much					

frustrated, because the child may not have the better future as you wish for?(আপনি কখনও খুব হতাশ বোধ করেছেন কারণ আপনি বাচ্চার জন্য যে উজ্জ্বল ভবিষ্যত চেয়েছেন হয়ত সে তা পাবে না?)					
Social Domain(সামাজিক ক্ষেত্র) 9.How often have you found that you became isolated just caring this child only?(আপনার কখনও এটা মনে হয়েছে যে শুধুমাত্র বাচ্চার যত্ন নিতে গিয়ে আপনি সকলের থেকে আলাদা হয়ে যাচ্ছেন?)					
10.How often have you been misbehaved by your husband/wife or by parents of disable child or caretaker of hostel because of the disable child? (আপনি কখনো প্রতিবন্ধী বাচ্চার জন্য আপনার স্বামী/স্ত্রী অথবা প্রতিবন্ধী বাচ্চার বাবা-মায়ের অথবা হোস্টেলের তত্ত্বাবধায়কের থেকে খারাপ ব্যবহারের স্বীকার হয়েছেন?)					
11.How often have you felt that you were unable to take social participation as being parent/caregiver? (যেহেতু আপনি বাবা-মা /পরিচর্যাকারী আপনি কখনো কি বোধ করেছেন যে সামাজিক অংশগ্রহনের জন্য আপনি অসমর্থ ছিলেন?)					

12. In your entire life,knowing about the child's disability have affected your decision to have the baby?(আপনার সমগ্র জীবনে বাচ্চাদর প্রতিবন্ধীতা সম্পর্কে জানার পর সেটা কি আপনার পরবর্তী বাচ্চা নেবার সিদ্ধান্ত কে প্রভাবিত করেছে?)					
Economical Domain(অর্থনৈতিক ক্ষেত্র) 13.How often have you felt difficulties with managing family expenses? (আপনার পরিবারের খরচ চালাতে গিয়ে কখনো সমস্যা বোধ করেছেন?)					
14.How much do the special needs of the child impact your economic burden?(বাচ্চার বিশেষ চাহিদা আপনার অর্থনৈতিক বোঝা কতটা প্রভাবিত হয়েছে?)	**N/A** **ACG**				
15. After the child was born, you left the job because you have to give more time to the child.(আপনার বাচ্চার জন্মের পর আপনি চাকুরী ছেড়ে দিয়েছেন কারণ বাচ্চাকে আপনার অধিক সময় দিতে হয়।)	**N/A** **ACG**				
16. Does the child receive help with wheelchair ___, OT ___, PT ___, ST___, Communication Aids from the beginning, _______?(প্রথম থেকে বাচ্চা কি হুইলচেয়ারের__ ,অকুপেশনাল					

থেরাপি__,ফিজিওথেরাপি__,স্পিচ এন্ড ল্যাংগুয়েজ থেরাপি__,যোগাযোগের মাধ্যমের_ সাহায্য পেয়েছিল?)					
Environmental Domain(পরিবেশগত ক্ষেত্র) 17. Since you have admitted the child to this school, you feel that the road/footpath for transfer of the child is leading to extra burden.(যখন থেকে আপনি বাচ্চাকে এই স্কুলে ভর্তি করিয়েছেন,আপনার মনে হয়েছে এই রাস্তাটা/ফুটপাত বাচ্চাকে স্থানান্তরের ক্ষেত্রে অতিরিক্ত বোঝা প্রদান করছে)					
18. How often the home/school environment makes you feel that you have to put your extra energy to control the wheelchair?(কখনো এই বাসা/স্কুলের পরিবেশ এটা মনে করিয়েছে যে হুইলচেয়ার নিয়ন্ত্রনের জন্য আপনাকে অধিক শক্তি দিতে হবে?)					
19.Does the child feels difficulty while going upstairs of the building for class even the building has accessible ramp?(প্রবেশযোগ্য ঢাল থাকা সত্ত্বেও বাচ্চা কি বিল্ডিং এর উপরে ক্লাশে যাওয়া কঠিন মনে করে?)					

20. How often do you feel the school environment for the child is friendlier?(কখনো কি আপনি অনুভব করেছেন যে স্কুলের পরিবেশ বাচ্চার জন্য বন্ধুত্বপ্রবন?)					