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**SLEEP DISTURBANCE AND QUALITY OF LIFE AMONG
CHILDREN WITH CEREBRAL PALSY**

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**“SLEEP DISTURBANCE AND QUALITY OF LIFE AMONG CHILDREN
WITH CEREBRAL PALSY”**

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Acronym

BHPI: Bangladesh Health Profession's Institute

BMRC: Bangladesh Medical Research Council

CP: Cerebral palsy

CRP: Centre for the Rehabilitation of the Paralysed

CSHQ: Children's Sleep Habits Questionnaire

CPQOL: Cerebral Palsy Quality of Life

IRB: Institutional Review Board

SPSS: Statistical Package for the Social Sciences

WHO: World Health Organization

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ABSTRACT

Purpose: The purpose of the study was to find out sleep disturbance and quality of life among children with Cerebral palsy. **Objective:** The objectives of this study were to find out the socio-demographic information. To elicit Quality of life in children with cerebral palsy child and examine relationship among sociodemographic information, sleep disturbance and quality of life. **Methodology:** The cross sectional study was chosen to carry out this study among 102 participants who were selected according to inclusion criteria. The “Children Sleep Habit Questionnaire” (CSHQ) And “Cerebral Palsy Quality of Life” (CPQOL) these two standard structured questionnaires were used to assess the sleep disturbance and quality of life among 102 participants. **Results:** This study found the sleep disturbance and quality of life among children with cerebral palsy. Among the 102 participants in this study, minimum age was of participant 4 and the maximum age of the participant was 12. Their mean age was 5.732 and standard deviation was 1.88. Statistically significant had found in between sleep and sociodemographic as age, occupation, cousin marriage, educational status, types of delivery and as well as association had found between sociodemographic and quality of life level as gender, occupation, educational level of parents, living area etc. **Conclusion:** Cerebral palsy is a condition which has an influence on sleep and quality of life. Sleep disorders are common in children with CP and that different factors, such as motor or cognitive impairment, sleep behavioral problems, bedtime, are important risk factors for the development of sleep disorders. Although none of these factors alone were associated with sleep disorders, the risk for developing abnormal patterns of sleep significantly increased with their presence. So early detection and proper management of this condition is essential during rehabilitation to prevent more complications and to improve their life quality.

Key words: Cerebral palsy, sleep disturbance, quality of life.

Word count: 11054

1.1 Background

Cerebral palsy is a group of permanent, but not unchanging, movement and/or posture and motor function disorders that are caused by a non-progressive interference, lesion, or abnormality of the developing/ immature brain and it is primarily based on motor function and posture disorders that start in early childhood and last until the end of life (Sadowska et al., 2022). The CP, which is one of the most frequent causes of chronic childhood motor dysfunction, may hinder social and cognitive development as well as the ability to carry out everyday tasks, necessitating multidisciplinary support and its effects are dependent on the CNS region injured, the length of time since the damage, and the severity of the injury; motor abnormalities are frequently accompanied with disturbances in sensation, cognition, perception, and behavior (Zuculo et al., 2014).

The motor disorders of cerebral palsy (CP) are frequently accompanied by disturbances of sensation, perception, cognition, communication, and behavior, by epilepsy, and by secondary musculoskeletal issues and it is distinguished by heterogeneity in risk factors, underlying specific etiology, clinical features, severity of functional limitations, associated and secondary conditions, treatment options, and evolution of the condition over the course of the individual's lifetime (Patel et al., 2020). A significant risk factor for CP, preterm delivery occurs in around 35% of cases, and the risk rises with decreasing viable gestational age (Maclenaan et al., 2015). The physiotherapist's job description covers a wide range of interventional tasks, from neonatal positioning to pre- and post-operative care for orthopaedic surgery, and, most frequently, ongoing individual therapy programs. And these therapy services are typically provided in the community, with children receiving care at home or in child development centers during their early years and in the classroom throughout their childhood and adolescence (Barber et al., 2010). Cerebral palsy is one of the primary causes of disability (Munyumu et al., 2018).

Cerebral palsy is a persistent qualitative motor impairment caused by non-progressive interference with brain development occurs before the central nervous system has fully

developed and there are six different types of CP according to the Little Club classification: spastic (hemiplegic, double hemiplegic, and diplegic); dystonic; choreoathetoid; mixed; ataxic; and atonic CP (Pakula et al., 2010). Children with cerebral palsy have trouble falling asleep and it is essential for a child's healthy physical and mental development as well as for the proper functioning of their nervous system. (Munyumu et al., 2018). According to the International Classification of Sleep Disorders, there are three categories of sleep disorders: parasomnias, mental or neurological diseases connected with sleep disorders, and dyssomnias. Depending on whether the child's sleep ailment is intrinsic to the child or related to the child's external environment, the dyssomnias are further categorized into intrinsic and extrinsic sleep disorders (Newman et al., 2006).

80 percent of the world's disabled people (adults and children) reside in developing nations, many of which are in Africa (Gladstone 2010). Due to the nature of their main brain lesion, children with cerebral palsy may have many risk factors for sleep disturbance. Multiple factors, such as mental retardation, visual impairment, seizures, anti-epileptic drugs, obstructive sleep apnea, restricted movement caused by contractures, spasticity and motor impairment, pain due to spasticity, dental caries, use of orthoses, etc., have been proposed as contributing factors to sleep disorders. Cerebral palsy sufferers' difficulty sleeping may lead to an increase in morbidity and mortality (Munyumu et al., 2018).

Children with cerebral palsy (CP) are more likely to experience sleep disturbances because of a number of CP-related issues. Numerous neurological conditions, including epilepsy, neurodegenerative diseases, and headaches, are included among the sleep disorders linked to mental, neurological, or medical conditions; cerebral palsy is not specifically mentioned (Simard Tremblay et al., 2011). Behavioral child and pharmacologic approaches have been shown to improve sleep in older children with CP and young typically developing children. (Tanner et al 2021).

Children with cerebral palsy are more likely to experience breathing problems related to sleep, such as obstructive sleep apnea. Children with cerebral palsy are more likely to have obstructive sleep apnea, which can also include obesity, poor central respiratory regulation, and drugs that weaken the muscles that keep the upper airway open that when the pharyngeal dilator muscles are unable to maintain the airway's patentness in the face of

inspiration's sub atmospheric pressure. At sites from the nose to the larynx, a variety of anatomical characteristics can increase resistance to airflow (Newman et al., 2006). An enormous strain is placed on the family and regular family life is disrupted by persistent sleep difficulties that last for several months (Munyumu et al., 2018). Young children's health and neurodevelopment depend on getting enough good sleep since it promotes development, neuroplastic reconfiguration, and learning (Tanner et al 2021).

Recent studies of children with cerebral palsy seem to suggest that this population is indeed at significant risk for sleep disorders (Simard Tremblay et al., 2011). Blindness or a severe visual impairment, which may coexist with CP, might impact melatonin secretion and the ability to perceive light, which can disrupt the timing and maintenance of sleep. In children with more severe total body involvement, glossoptosis and recurrent aspiration pneumonia owing to gastro-oesophageal reflux are prevalent and can cause breathing problems during sleep (Newman et al., 2006).

Another theory is that these comorbidities, as well as sleep issues, can all be related to one another. The effects of sleep disturbances are wide and have an impact on the family as well as the child (Pakulo et al., 2010). Identification and early therapy of concomitant disorders such as gastric reflux, hypersalivation, and obesity are crucial components of treating obstructive sleep apnea in kids with cerebral palsy. The concomitant epilepsy, intellectual disability, primary sensory impairment (such as vision or hearing), aberrant tone, and pain are comorbidities frequently observed in children with cerebral palsy. A more severe level of intellectual disability was found to be an indicator of an increased amount of nighttime sleep in a study done in children with abnormal development, and was therefore termed a "protective factor" for the incidence of sleep difficulties. Epileptic disorder results in a deficiency in endogenous sleep regulation, as well as other symptoms including the presence of nocturnal seizures or the use of antiepileptic medications that cause sleep issues. (Elisabeth Simard et al., 2011).

The World Health Organization defines quality of life (QoL) as "individuals' perception of their position in life in relation to their goals, expectations, standards, and concerns and in the context of the culture and value systems in which they live." Because it can give a wide subjective indication of a person's well-being across various life domains, including

physical health and social and emotional well-being, quality of life is a particularly relevant and significant term in the setting of children with cerebral palsy (Gilson et al., 2014).

Caring for a child with cerebral palsy (CP) can effect on the quality of life (QOL) of caregivers (Ruberto et al., 2016). It is a broad, multifaceted concept that incorporates subjective assessments of both the good and bad things in life. Early conceptions of quality of life were mainly dependent on functioning, and measures that claimed to quantify it were more concerned with a person's physical well-being and functional constraints (i.e., what they can and cannot do) than with their overall well-being or personal experiences. CP is a long lasting and incurable condition, the treatments are used in an pretent to improve general health condition and well-being of the individual (Zuculo et al., 2014).

A clinical examination must consider the health and daily functioning of the patient, and assessing the patient's quality of life can help medical practitioners decide how to best design suitable, tailored treatment measures. Today, there are a variety of general and condition-specific scales that can be used to assess a child's quality of life (QOL) who has cerebral palsy. These scales come in child self-report or parent proxy versions. Children and their families may also gain from the knowledge that quality of life assessments can offer, especially if favorable results are seen in some domains or by encouraging talks about the appropriateness of treatments (Gilson et al., 2014).

The concept of QOL refers to objective and subjective indicators of happiness and satisfaction, and they may be measured by different instruments, being most of them self-report questionnaires supposedly to be answered by the individual themselves or by a representative, in cases there are limitations due to motor impairment or in cases in which the perception of the individual leads to limitations in obtaining the answers. , there is probably an aggravating factor in the aspects of QOL of an individual with CP, already so much affected by motor impairment.(Zuculo et al., 2014).

Children with CP are at risk of sleep disorders and decreased QOL. It was hypothesized that presence of sleep problems would be associated with impaired QOL in children with CP. Excessive daytime sleepiness (EDS)—often a consequence of SDB and otherwise interrupted sleep—has been posited as an important symptom in relation to quality of life

(QoL). There is significant difference in quality of life (QOL) between children with CP and normal developing peers (Samota et al., 2021).

Adenotonsillectomy, the first line treatment for SDB in children, as well as continuous positive airway pressure may lead to improvements in QoL dimensions for children. Sleep disorders and decreased QoL are risks for children with CP. Strong clinical findings correlate poor sleep quality to lower QoL overall, and there is limited but consistent research on the negative impact of SDB on QoL. However, there is little research that looks at these correlations in CP children. Our hypothesis was that children with CP who had sleep issues would have a lower quality of life (Sandella et al., 2011).

There is probably an aggravating factor in the aspects of QOL of an individual with CP, already so much affected by motor impairment, given that sleep disorders usually cause decrease in motivation and concentration, memory deficit, daytime sleepiness, mood shifts, and immunity decline. The occurrence of sleep disorders negatively affect the QOL of individuals with CP (Zuculo et al., 2014). No previous research has looked specifically at daytime sleepiness symptoms as a predictor of QoL. Previous studies of relations between sleep disorders and QoL have largely focused on SDB and its treatment in otherwise typically developing children (Gilson et al., 2011).

1.2 Rationale

Cerebral palsy is defined as a group of disorders of movement and posture causing activity limitations that can be attributed to non-progressive disturbances that occur in the developing fetal or infant brain. Recent studies on children with cerebral palsy seem to indicate that this population is at higher risk for sleep disorders. Children with cerebral palsy may have multiple risk factors for sleep disturbance because of the nature of their primary brain injury. Similarly, quality of life is a very relevant and important construct in the context of children with cerebral palsy because it can provide a broad subjective indication of their well-being across several life domains such as physical health and social and emotional well-being. Quality of life is considered a broad and multidimensional concept that includes subjective evaluations of both the positive and negative aspects of life. Sleep is vital for a child's normal physical growth and psychological health and plays a critical role in the neurological development. Sleep deficiency in children with cerebral palsy significantly affects the child's physical, emotional and cognitive development and performance. It was hypothesized that presence of sleep problems would be associated with impaired QOL in children with CP. By this study Physiotherapist and other professionals will aware about the sleep disturbance and quality of life with children of cerebral palsy and it can play a role in resolving.

1.3 Research question:

What are the sleep disturbance and quality of life in children with cerebral palsy?

1.4 Study objective:

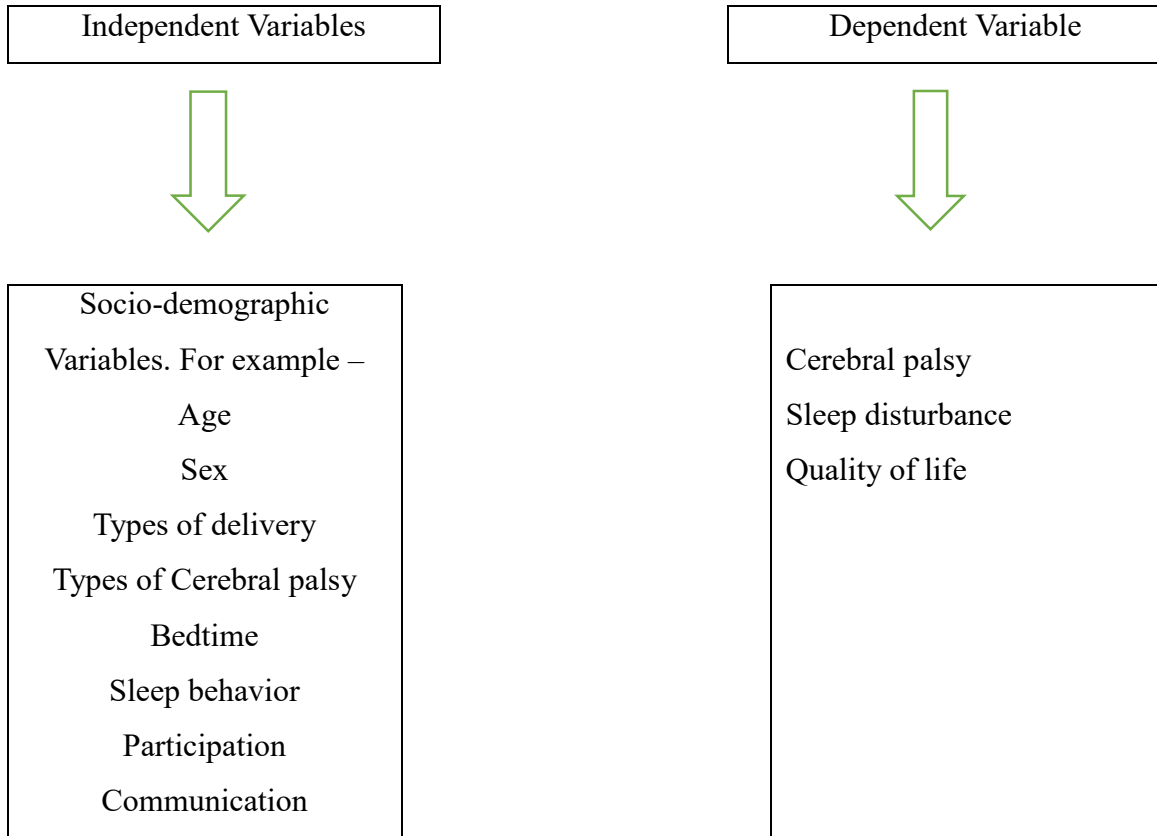
1.4.1 General objective:

To find out sleep disturbance and quality of life in children with cerebral palsy.

1.4.2 Specific objective

- i. To find out sociodemographic information.
- ii. To find out sleep disturbance of children with cerebral palsy.
- iii. To find out association between sociodemographic information and sleep disturbance of children with cerebral palsy.
- iv. To find out association between sociodemographic information and quality of life in children with cerebral palsy.

1.5 Conceptual framework:



1.6 Operational definition

Cerebral palsy: Cerebral palsy (CP) is a group of disorders that affect a person's ability to move and maintain balance and posture. CP is the most common motor disability in childhood. Cerebral means having to do with the brain. Palsy means weakness or problems with using the muscles.

Sleep disturbance: Sleep is vital for a child's normal physical growth and psychological health and plays a critical role in the neurological development. Unresolved sleep disturbances which exist for many months place a heavy burden on the family and disrupt normal family life. Children with cerebral palsy may have multiple risk factors for sleep disturbance because of the nature of their primary brain injury.

Quality of life: Quality of life is considered a broad and multidimensional concept that includes subjective evaluations of both the positive and negative aspects of life. It embraces the notion of holistic well-being and encompasses elements about general functioning and health, but also extends beyond these to include a person's appraisal of their life experiences and social and emotional well-being.

Children with neurodevelopmental problems, such as cerebral palsy, which is a collection of movement and posture disorders that limit activity and are caused by non-progressive changes in the fetal or infant brain, are affected (Fitzgerald et al.,2009). Sleep difficulties affect about 25% of children who are developing normally, and they can affect up to 45% of children with cerebral palsy (CP) (Samota et al., 2021).

More recently, a survey from the Government of Canada revealed that by 2031, there will be three times as many adults over 65 living with CP (Amankwah et al.,2020).

Prevalence estimates of CP range from 1.5 to more than 4 per 1,000 live births or children in a specific age range, according to population-based research from around the world and the frequency of CP has not decreased despite recent improvements in obstetric and neonatal care. Despite better prenatal and obstetric care, the incidence of CP has not decreased. The frequency of CP in term infants has remained constant, even in facilities with ideal perinatal care environments with delivery asphyxia being a relatively rare occurrence. Because survival rates have increased over the past few decades, the prevalence has grown globally as a whole (Palisano RJ et al., 2018).

In spite of the fact that newborn mortality has decreased, CP incidence and severity have actually increased. Compared to term births, the incidence is significantly higher in preterm babies. Boys are more likely than girls to have cerebral palsy, and black children are more likely to have it than white children (Mayo clinic Infant Jaundice, 2019).

In western nation, the prevalence of cerebral palsy is 2-2,5/1000, in various nations, it is 1 to 5 per 1000 newborn and Asia does not have any trustworthy statistics. Some children's CP incidence has decreased as a result of better medical care and they would have died at a young age in the past are now alive thanks to medical advancements (Palisano RJ et al., 2018).

Disorders of sleep initiation and maintenance, sleep-wake transition disorder, excessive drowsiness, and arousal disorder are more common in kids with CP (Samota et al., 2021). Cerebral palsy patients' sleep disorders may raise their risk of morbidity and mortality. To

facilitate the formulation of treatment plans or treatments, information addressing sleep disturbances among children with CP in Uganda is, however, inadequate. As a result, Munyumu et al. (2018) examined the prevalence and contributing factors of sleep problems among Ugandan children with cerebral palsy aged 2 to 12 years. Children with cerebral palsy (CP) may experience sleep issues that exacerbate pre-existing CP-related morbidity, such as impaired physical and cognitive performance, as well as decreased quality of life for the child and family.

Over the past few years, there has been a steady rise in interest in the subject of sleep disturbances in kids with neurodevelopmental difficulties. However, the exact nature and frequency of sleep problems experienced by children with CP and the key predisposing factors to these sleep disturbances remain unclear (Horwood et al., 2018). In the United States, almost 500,000 persons with CP can currently anticipate near-typical lifespans; nevertheless, they also have a higher likelihood of developing secondary disorders earlier than their peers without CP (Peterson, Gordon and Hurvitz 2013).

The prevalence of sleep disorders has yet to be evaluated in Canadian children with CP. Similarly, there is a lack of understanding about other sleep-related characteristics of children with CP, such as the frequency of nighttime pain, need for repositioning by caregivers, use of melatonin, and sleep duration. In preschool- and school-aged children with CP in Canada, the prevalence of sleep disorders, the frequency of other sleep-related characteristics (e.g., nighttime pain, melatonin use, sleep duration) and the association of child and sleep-related characteristics with sleep problems (Horwood et al., 2018).

A study conducted by Zuculo et al. (2014) with seventy-eight cerebral palsy patient to find out sleep pattern and the quality of health. The results of this study showed that 60.4% of them present sleep disorders, which estimates that sleep problems affect approximately 33.0% of the population with cerebral palsy and respiratory one of the most common disorder, with 25.6 and 34.9%, respectively. CP may present deficit in respiratory movements, as a consequence of tonus disorders and posture during breathing and lack of coordination of the respiratory movements would lead some individuals with CP to a high risk of obstructive sleep apnea, assessed in this study using the SDSC in the RSD parameter.

A review study conducted by Lelis et al. (2016) to measure their nature of sleep disorders for children with CP and factors related to their sleep disorders. They have identified eleven types of sleep disorders and twenty-one factors linked to sleep disorders for children with CP. From previous descriptions of sleep disorders in children with CP, thereby potentially increasing awareness of care providers about sleep problem management are noticed. One study showed that abnormal sleep score occurred by mental retardation (Wayte et al., 2012).

Some studies included that primary visual impairment enhances risk for the development of sleep disorders. Between 20% and 50% of children have cortical visual impairment (Sellier et al., 2012). Their review suggests cognitive impairment and mental retardation have been associated with sleep disorders in children with CP. Parental reports included that dyskinetic CP children presented significantly higher scores for sleep-wake transition disorders and an abnormal sleep score was significantly associated with level five on the gross motor function classification system (GMFCS). Another study observes positively associated between sleep disorders and level of motor functioning by using GMFCS (Elsayed et al., 2013).

Insomnia and sleep disordered breathing (SDB) were indicated with GMFSC grade V and IV while sleep bruxism was more common in grade III. Another study investigates about children's ages and GMFCS-levels, resulted in no statistically significant differences in sleep disturbance. Some study indicated that antiepileptic medications can increase the risk of sleep problems or demonstrate no association (Romeo et al et al., 2014). A prospective cohort study with 31 children with abnormal sleep scores, 14 children with active epilepsy, four got controlled epilepsy, and 13 showed no signs of epilepsy. No specific relationship was observed between the type of antiepileptic agent and sleep scores (Lelis et al., 2016).

A study conducted by Radsel et al. (2016) with 122 cerebral palsy patient to find out health-related quality of life of children and adolescents with cerebral palsy. In this study showed that the exception of social involvement and motor performance, children and adolescents with CP scored similarly to the general population in studies that compared their Health Related Quality of Life (HRQoL). In longitudinal investigations, HRQoL in childhood and adolescence showed strong correlations and also as predictors of lower HRQoL, pain, parenting stress, and psychiatric issues were discovered. Although motor disability

decreased engagement and functioning, it had significantly less of an impact on psychosocial wellbeing.

A study conducted by Zuculo et al. (2014) with the questionnaire of sleep habits showed that 23.2% of the participants with CP wake up in the middle of the night and that 37.2% of them snore. On the basis of the results presented, sleep disorders and the QOL parameters showed negative correlation, indicating that the low sleep quality in this population that affects their physical and emotional well-being.

Most HRQoL measurement instruments currently in use examine an objective interaction between body structure, function, and participation rather than HRQoL (a subjective perspective) (Fayed et al., 2012). Many HRQoL measures are flawed because they only focus on how frequently patients express sadness and dissatisfaction with their participation in daily activities, rather than including indicators that measure wellbeing (positive emotions and satisfaction about daily activities, relationships, and life in general) (Wates et al.,2007).

It is consistent with the data that overall QoL can be influenced by both physical and psychological factors and that children with CP can have good QoL that is not always correlated with the severity of their impairment. The CP literature also makes provisions for various QoL informants, including both parents and children or just the former. In the management of severe CP, where the ability to self-report may be hampered by cerebral and/or linguistic impairments, the use of parental proxy reports is particularly crucial. Proxy reports, however, might constitute a source of systematic bias due to their reliance on second-hand information and insider information. Additionally, parents are not always able to recognize QoL issues that their child prioritizes (Zuculo et al.,2014).

In order to ascertain whether children were able to self-report, the SPARCLE project collected QoL reports from as many kids as it could, using a standardized measure of response competence for those with concomitant intellectual disability (Dickinson et al., 2007). To make reliable comparisons of QoL across the range of children with CP, proxy reports for the entire population must be used, as one-third of the children were unable to self-report. Age, gender, illness severity, and pain levels in children have been demonstrated to affect parents' assessments of their children's quality of life in a variety of

chronic disorders, including CP. Previous research offered inconsistent results about the association between the severity of motor impairment and quality of life, and it was proposed that domains connected to physical symptoms may be more negatively impacted than domains related to social or emotional functioning (Varni et al., 2005).

This may be due in part to the ease with which physical rather than psychological symptoms can be reported. The stress of providing care as well as the parents' own mental health and well-being may have an impact on how parents perceive their children's quality of life (Lewes et al., 2006). Studies on the quality of life (QoL) of children with cerebral palsy (CP) have primarily concentrated on small cohorts of kids chosen from clinics with homogeneous degrees of impairment severity rather than the spectrum of impairments, and little is known about the influence of associated impairments in this population, despite the high prevalence of such difficulties. It is crucial to be able to identify children who are more likely to have poor QoL in clinical settings, hence it is vital to specifically identify the characteristics linked with the lowest QoL in each domain. According to the QoL dimensions that were looked at, we predicted that different levels of impairment severity would have varied effects on QoL components, and vice versa. We also anticipated that parental stress would be linked to parent proxy-reports of child QoL (Arnaud et al., 2010).

A study conducted by Linda et al (2018) to assess the prevalence of sleep disorders and sleep-related characteristics in Canadian children with CP. In their cohort of 150 children with CP aged 3-12 years, 1 in 5 children had serious sleep disturbances (i.e., an abnormal total score on the SDSC), with rates nearly three times higher in school-aged compared to preschool-aged children (28.6% vs. 10.6%, respectively). In their study showed that 44.0% had clinically significant symptoms of one or more sleep disorder. Pain was the strongest predictor of having an abnormal total score and DIMS, adjusted for age group and degree of motor impairment had found. They also found that many children in their study were on melatonin or had a history of melatonin use. In their study, they showed that a strong association between melatonin use and having a sleep problem; this is likely due to the fact that the children had symptoms of DIMS or other sleep problems and were on melatonin for that reason, whether prescribed by their doctor or parental purchase of it over the

counter. Health care professionals caring for this population should regularly search about sleep problems and pain.

A cross-sectional data conducted by Makris et al. (2019) with 11 independent studies, comparing self and parent-reported QoL among the young CP population to neuro-typical peers, were quantitatively evaluated. Physical health and wellbeing was identified as a main area of difference for both groups. Psychological and social QoL fields for children and adolescents with CP were also rated lower than peers, although this pattern was not suitable across included studies. Notably, Physical and psychosocial difficulties identification found more easily by the parents that their child may experience (Rapp et al.,2017).

The current research highlight challenges in the selection of the most appropriate and reliable assessment tool when measuring QoL in children with cerebral palsy. As the World Health Organisation thinks, QoL is subjective. So, self-report should be the first choice according to them. Self-report assesses offer the child an opportunity to reflect on their own personal experiences. Parents can provide an instructed to how a disability may impact their child's QoL, there is also evidence that parental distress can negatively influence of QoL ratings (Davis et al., 2012). Level of parent and child covenant appeared to be higher when comparing objective physical domains as aversed to subjective psychological and social aspects. As a result, an accurate QoL assessment should take into account a variety of (physical, psychological, and social) dimensions of health status and wellbeing rather than only concentrating on the specific symptoms and effects associated with CP (such as mobility, weakness, and ability to take care of oneself). This comprises areas that are thought to be essential to a child's welfare, like a strong emotional support system made up of friends and family members and a successful educational experience (Gilson et al.,2014).

A study conducted by Adiga et al. (2014) found that eleven children (22%) had SD (sleep disturbance) as one of the presenting complaints and eighteen children (36%) had pathological sleep. DIMS was the most frequently reported SD (n = 25, 50%). Third- five kids (or 70%) were sleeping in the same bed as their mothers. In 70% of cases, people shared beds. Sharing beds with the kids were 23 out of 25 caregivers (92%) who had sleep

disturbances. SD and bed-sharing were significantly correlated in carers. Eight kids (16%) were wearing orthotics at night. Although it was anticipated that children wearing orthoses at night would experience a higher incidence of SD. A similar pattern has also been noted in other earlier research. In contrast to several earlier investigations, twenty children (40%) in our sample had dental caries.

In contrast to an earlier study, when bed-sharing was linked to higher DIMS, SBD, SWTD, etc., our investigation found no association between bed-sharing and problematic sleep individual SD in CP patients (Moi et al., 2012).

Physical, mental, and social well-being are all included in the subdomain of quality of life known as quality of life related to health (QOL). Health-related QOL has been elevated to a significant outcome indicator for kids with CP. According to research, children and teenagers with CP have lower functional and psychosocial quality of life than their peers without the condition (Tsoi et al.,2012). Traditional CP therapies have been linked to enhancements in the functional quality of life of patients, but these therapies have had less of an effect on psychosocial QOL. In particular, earlier research discovered a tenuous link between psychosocial QOL and CP severity assessments. This has prompted a demand for additional research into other patient-level characteristics that may have an impact on psychological QOL. Lower QOL may be brought on by the comorbidities, or the coexistence of numerous of these impairments. If this is the case, healthcare measures that aimed to lessen CP comorbidities may benefit patients' quality of life (Tessiere et al., 2017).

Single-parent families indicate a greater prevalence of sleep disordered breathing (SDB), suggesting that socio-environmental factors including family structure and socioeconomic status may possibly affect risk in the CP population. Lower sleep quantity and duration are linked to preterm gestation, a perinatal risk factor for cerebral palsy, however the findings related low birth weight are less certain. It has been suggested that excessive daytime sleepiness (EDS), which is frequently a result of SDB and other sleep disruptions, is a significant symptom in connection to quality of life (QoL) (Newman et al.,2006). Daytime drowsiness symptoms have not been explicitly studied as a QoL predictor in prior studies. SDB and its treatment in otherwise typically developing children have been the main topics of previous investigations on the relationships between sleep problems and quality of life.

Continuous positive airway pressure (CPAP), the first-line treatment for SDB in children, as well as adeno-tonsillectomy may improve certain aspects of QoL for both children and their caretakers (Hsiao et al.,2008).

Reimer and Flemons emphasized the need for more research to expand the concept of "sleep disorder" to encompass symptoms other than apnea as well as the need for more precise QoL categories in their review of sleep disorders and QoL. There is a dearth of research on sleep disorders and CP, and there are no prevalence figures for SDB in CP. Incontinence, self-concept ratings, and GMFCS level were significant predictors of QoL (Soyupek et al., 2010). The results of the one prior study that examined the relationship between SDB treatment and QoL in the CP population show that treating SDB may improve QoL. The wide variety of physical, cognitive, and sensory problems linked to CP makes it challenging to assess children's quality of life. The majority of studies of children in grade school use parent proxy ratings, however there are methodological variances, such as different emphasis on health status in the measurement of QoL and different choice of informant. According to conflicting findings, children with CP have lower QoL than their usually developing classmates (Sandella et al., 2011)

3.1 Study design:

The researcher chosen a cross-sectional study to conduct the investigation. In this study a cross sectional study design was used to find out sleep disturbance and quality of life among children with cerebral palsy. This study design was appropriate to find out the objectives. The data was collected at the same time or within a short time. A cross-sectional design gives a snapshot of the study's variables at a certain point in time.

3.2 Study site:

Data was collected at the CRP Paediatric unit in Savar, Dhaka by the researcher. This study were conducted on the mothers of children with cerebral palsy at the Centre for the Rehabilitation of the Paralysed (CRP), Savar, Dhaka. The parents showed no difficulty in providing information to the researcher.

3.3 Study population:

A population was the total group, set of events of the observation on which a study is conducted. It was the population the researcher was interested in and wanted to generalize the study's findings to. The study's sample population were chosen from the mothers of cerebral palsy children those were received treatment at CRP.

3.4 Sampling technique:

The convenience sampling method was used to choose the sample for this study. A convenience sample was a collection of people who (conveniently) meet the criteria for the study.

3.5 Sample size:

In the case of a cross-sectional study, the finite population correction equation was

$$\begin{aligned}n &= \frac{Z^2 P \times Q}{d^2} \\&= \frac{(1.96)^2 \times 0.34 \times 0.66}{(0.05)^2} \\&= \frac{3.84 \times 0.34 \times 0.66}{0.0025} \\&= \frac{0.8616}{0.0025} \\&= 344\end{aligned}$$

Here,

Z (confidence interval) = 1.96

P (prevalence) = 0.34

Q = 1 – P

= 1 – 0.34

= 0.66

The actual sample size was, n = 344

But due to time limitation 102 samples (mothers of cerebral palsy children) were taken in total for this study from 16-05-2023 to 16-07-2023.

3.6 Inclusion criteria:

- Children with Cerebral palsy and diagnosis was confirmed by pediatrician.
- Mother who has children with Cerebral Palsy age between 4 to 12 years.
- Interview has taken only from the mother who was willing to participate in the study.
- All types of cerebral palsy children can participate in the study.
- Those mothers whose child take treatment in CRP.

3.7 Exclusion criteria:

- Other neurological condition except Cerebral palsy and diagnosis was not confirmed by pediatrician.
- Mothers who was mentally ill.
- Mothers who was Cerebral Palsy children age more than 12 years
- Mothers who was unwilling to participate in this study

3.8 Measurement tools:

The study required a Bengali Consent Form and Questionnaire (Children Sleep Habit Questionnaire and Cerebral Palsy Quality of Life), as well as other materials such as a pen, pencil, eraser, clip board, white paper and note book. Demographic data were collected based on a literature review and the study objectives. Parents were asked about their age, gender, marital status, occupation, types of delivery, educational level, monthly family income etc.

Children Sleep Habit Questionnaire (CSHQ)

The Children's Sleep Habits Questionnaire is a psychological questionnaire designed to measure sleep behaviors in children ages 4–12. The questionnaire is about your child's sleep habits and possible difficulties with sleep. Think about the past week in your life when you answer the questions. If last week was unusual for a specific reason, choose the most recent typical week. Unless noted, check Always if something occurs every night, Usually, if it occurs 5 or 6 times a week; Sometimes if it occurs 2 to 4 times a week; Rarely if it occurs once a week, and Never if it occurs less than once a week. This questionnaire measured by different habit of sleep such as; bedtime, sleep behavior, waking during the night and morning wake up.

Cerebral palsy quality of life (CPQOL) Questionnaire

QOL was assessed using the CPQOL-CHILD, a questionnaire for children with cerebral palsy. Two versions of the questionnaire were available: the child self-report version was for children aged 9 to 12 and comprises 53 items, while the parental proxy version was for children aged 4 to 12. The CPQOL-CHILD parent proxy version was utilized. Version in Hindi was verified. All items in various domains were rated from 1 to 9, where 1=very unhappy and 9=very happy, but in pain and impact of disability domain rating is 1=not upset and 9=very upset. In this questionnaire, we wanted to ask participants some questions about how you think your child FEELED about aspects of their life such as family, friends, health and school. Each question began with “How do you think your child FEELS?” It was important for you to report how you believe your child feels. Sometimes it was difficult to know how your child is feeling. Please just try and answer as best as you can. For each question we wanted you to circle the best number that shows how you think your child FEELED. You could circle any number from 1 (Very unhappy) to 9 (Very happy). This questionnaire was measuring how your child feel, not what they could do.

3.9 Data collection:

The participant has the right to refuse to respond to any question when completing the questionnaire, the researcher explained at the started of the study. They were free to leave the study whenever they like. The purpose of the study was also made clear to all participants by the researcher. Participants received assurances that no personal information would be made public. Using a written consent form, the researcher obtained each volunteer participant's consent. Following the participants' agreement, a standard questionnaire was utilized to determine the complaint and gather demographic data. The format of the questions was in Bangla. The interview was performed face-to-face, and questions were posed by the researcher. Only the physical conditions was taken into account. To ensure the interviewee maintained appropriate attention, distracting stimuli were taken away. As far as possible, the interviewee was questioned alone with their consent because sometimes close relatives can provide guidance for their answers. During the interview, the researcher established a rapport and clarified her questions. The best method for securing participants' full cooperation in a survey is face-to-face interviews.

Face-to-face interviews were also useful for describing population characteristics. Face-to-face interviews were conducted to gather particular information that will be utilized to describe the demographic in discussion. In order for the patients to fully understand the questions and provide accurate answers, the questions were occasionally described in the native language of the participants, depending on their degree of comprehension. To prevent inaccuracies, the researcher independently collected all of the data.

3.10 Data analysis:

To analyze the data, descriptive statistics were utilized. According to Hicks (2009), descriptive statistics refers to techniques for describing a group of findings in terms of its most interesting aspects. Statistical Package for the Social Science (SPSS) version 25 was used to analyze the data. The researcher created a computer-based data definition record file that contains a list of the variables in order after labeling them in a list. The researcher defined the types, values, decimal, label alignment, and measurement level of the data and entered the names of the variables in the variable view of SPSS. The next step was to organize up new data files and verify that all data had been appropriately entered from the questionnaire sheet into the SPSS data view before examining the inputted data set. The raw data were then prepared for SPSS analysis. On frequency and sensitivity tables, data were gathered. The mean plus standard error (SE) for each variable was used to calculate central tendency. One-way anova tests were used to explore how numerical variables were related. Descriptive statistics were used to assess the data, determine percentages, and present it using table, bar graph, pie chart, etc. The pie chart and bar graph were embellished using Microsoft Office Excel 2017. There were quantifiable data in the study's findings. A lot of information was gathered during this study.

3.11 Ethical consideration:

The researcher followed the following ethical guidelines: The researcher adhered to the guidelines set forth by the WHO and the Bangladesh Medical Research Council (BMRC). The BHPI physiotherapy department received a research proposal for approval, which was granted by the faculty. The proposal also received initial approval from the course coordinator and the research project supervisor before the study could be taken out. The Institutional Review Board (IRB) of Bangladesh Health Professions Institute (BHPI) received the dissertation proposal, together with the methodology, for an oral presentation defense. The Institutional Review Board then gave its approval and gave permission for this research to proceed. The researcher began the study after receiving approval from the academic center to do it. The Pediatric Department of CRP, Savar has given the researcher permission to collect data. Before inviting them to participate in the study, the participants would be informed. A written consent form was utilized to get each participant's consent for the study, and for participants aged 4 to 12 years-old, the researcher also obtained approval from their parents. The researcher made sure that each participant was made aware of their rights and liberties as well as the purpose and goals of the study. The researcher made sure the study didn't hinder the organization (CRP). Highly maintained confidentiality for all types. The researcher took care to keep all information secret. After learning the academic and clinical guidelines for conducting the study, including what should be done and what should not, the researcher was qualified to conduct the study. All participant rights were protected, and the researcher was obligated to respond to any participant questions about the study.

3.12 Informed consent:

In this research, consent forms were given to potential participants after they verbally agreed to participate in the study and understood its objectives. They were informed that their participation was entirely up to them and that they might revoke it at any time. Additionally, they were informed that privacy would be respected. Though they won't be named, information may be published in any writing or presentations. The findings of the study might not directly benefit them, but they had positive consequences on the population of physiotherapists.

4.1 Socio-demographic Information

A total 102 subjects were studied in this study. Necessary information was collected from the respondents and after analysis data was presented as tables and graphical from below.

4.1.1 Age

Among the 102 participants in this study, 4-6 years old made up 71 participants, 6-9 years old made up 26 participants and 9-12 years old made up 5 participants.

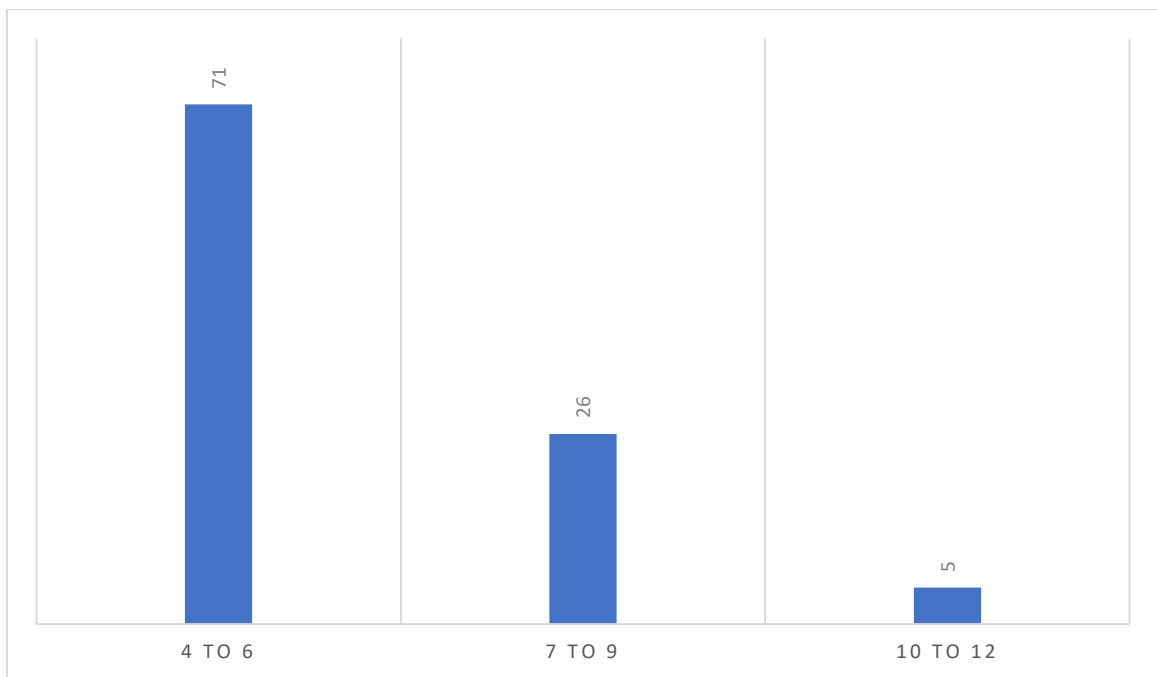


Figure -01: Age of the participants

4.1.2 Gender

Among the 102 participants 63% (n=64) were male and 37% (n=38) were female in this study.

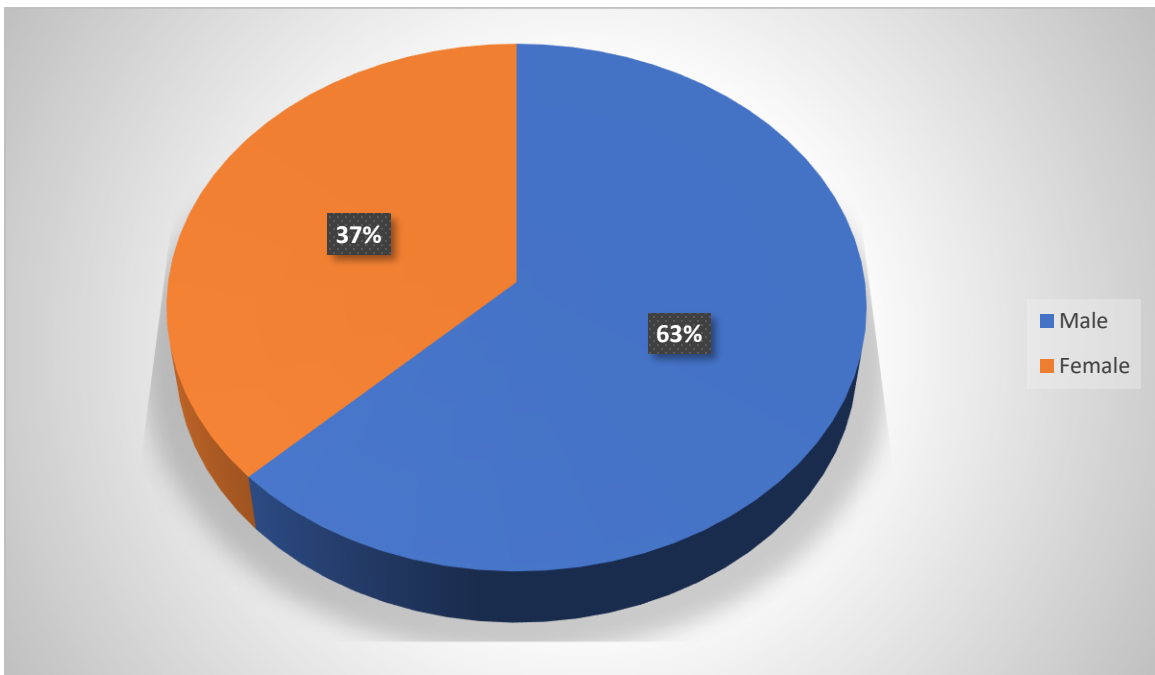


Figure 02: Gender of the participants

4.1.3 Living area

Among the 102 participants 50% (n=51) were rural, 33% (n=34) were urban and 17% (n=17) were semi-urban.

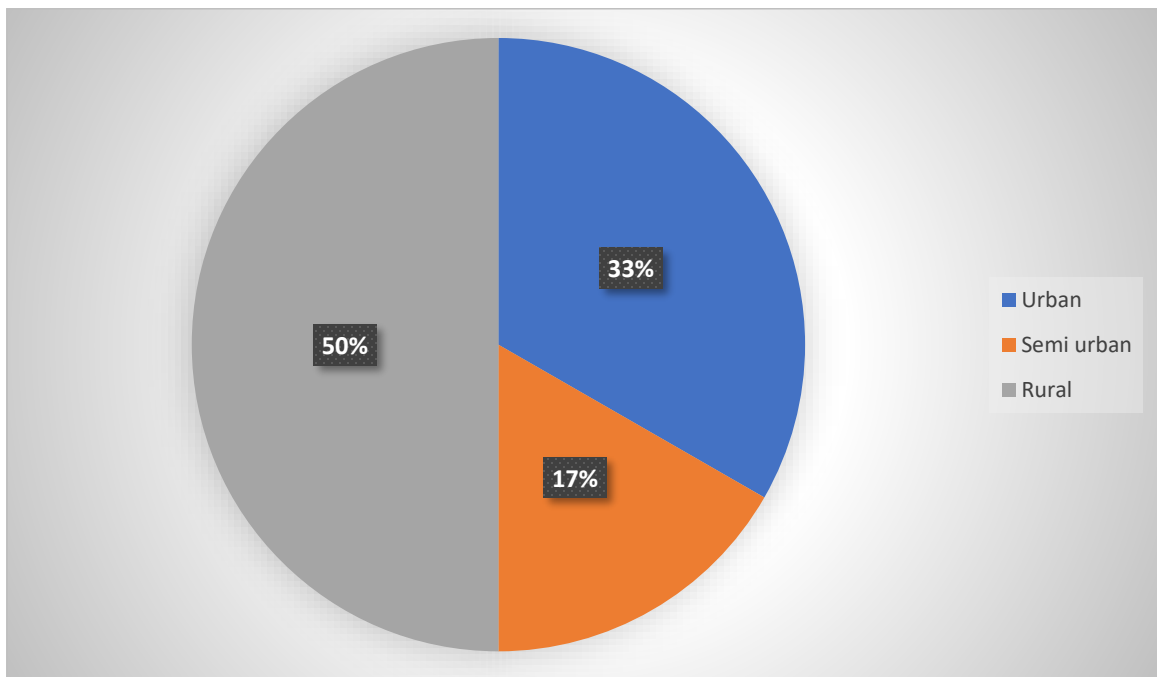


Figure 03: Living area

Table 01: Occupation of respondent

Occupation of respondent	Number	Percentage
Govt. worker	5	4.9%
Businessman	19	18.5%
Laborer	1	1%
Unemployment	12	11.8%
Housewife	51	50%
Teacher	2	2%
Others	12	11.8%

Among the 102 participants 4.9% (n=5) were Govt. worker, 18.5% (n=19) were Businessman, 1% (n=1) were Laborer, 11.8% (n=12) were unemployment, 50% (n=51) were Housewife, 2% (n=2) were Teacher and 11.8% (n=12) were others such as students etc.

Table 02: Educational status

Educational status	Number	Percentage
Primary	20	19.7%
High school	3	2.9%
SSC	49	48%
HSC	9	8.8%
Hon's	11	10.8%
Masters	10	9.8%

Among the 102 participants 19.7% (n=20) were primary, 2.9% (n=3) were high school, 48% (n=49) were SSC, 8.8% (n=9) were HSC, 10.8% (n=11) were Hon's and 9.8% (n=10) were masters.

4.1.4 Cousin marriage

Among the 102 participants 12% (n=13) allow cousin marriage and 88% (n=89) don't allow cousin marriage.

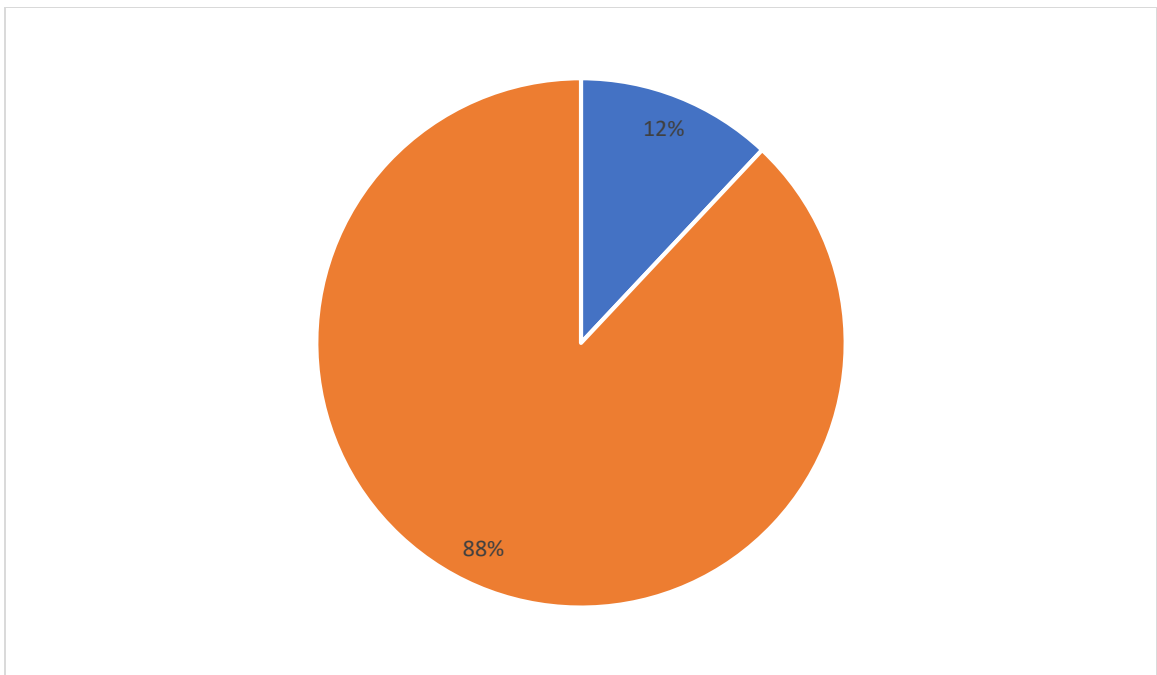


Figure 04: cousin marriage

4.1.5 Types of delivery

Among the 102 participants 61% (n=63) normal vaginal delivery, 39% (n=39) cesarian section and there was no any forceps delivery.

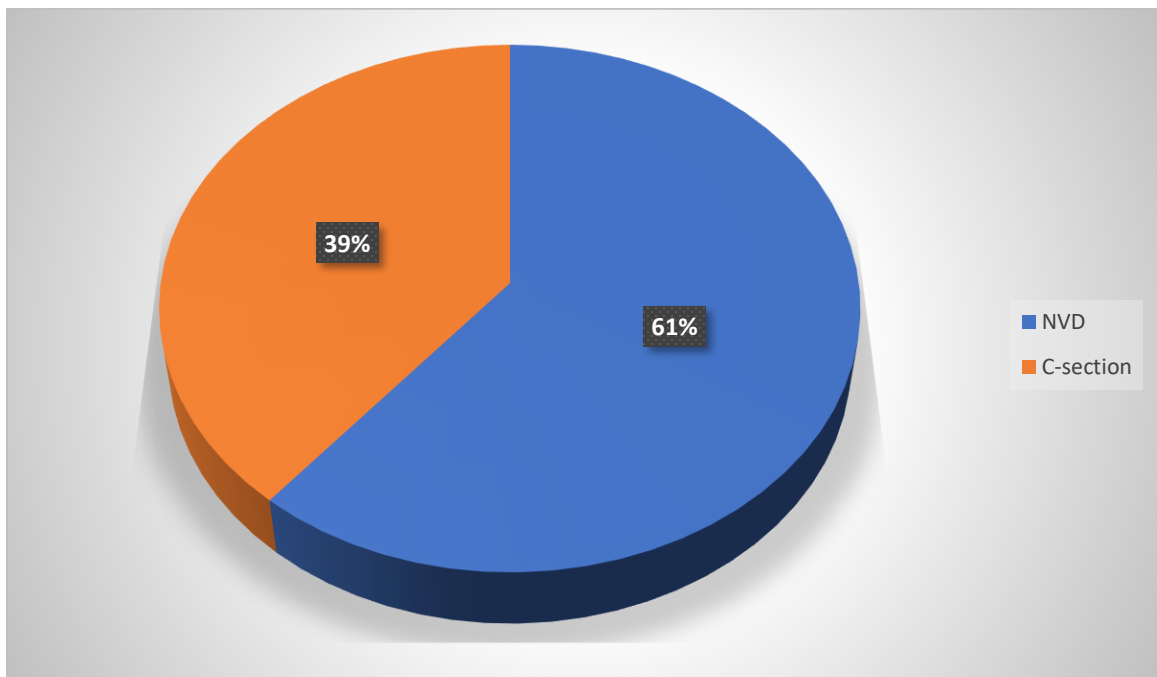


Figure 5: Types of delivery of the participants

4.1.6 Types of cerebral palsy

Among the 102 participants 79% (n=81) were spastic, 19% (n=19) were athetoid and 2% (n=2) were ataxic.

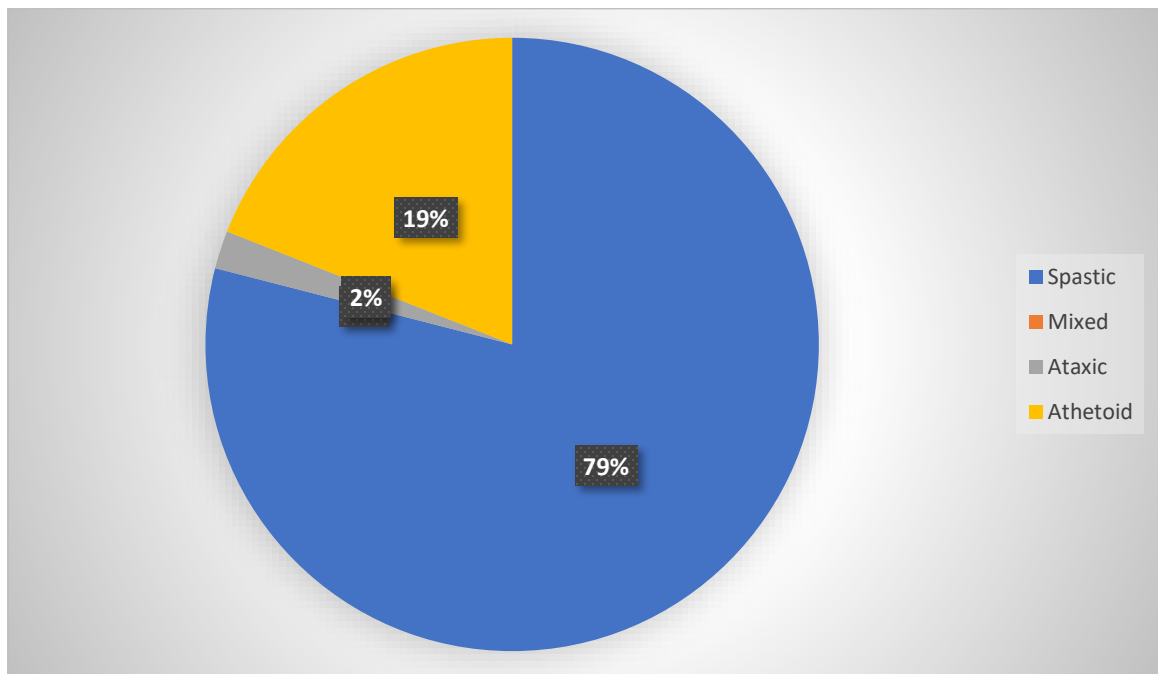


Figure 6: Types of cerebral palsy of the participants

4.2 Sleep Disturbance Questionnaire part

❖ Bedtime

4.2.1 Bedtime child falls asleep alone in own bed

In this study it was found that about 3% (n=3) participants selecting never, 6% (n=6) participants selecting rarely, 25% (n=26) participants selecting sometimes, 3% (n=3) participants selecting usually and 63% (n=64) participants selecting always falls asleep alone in own bed.

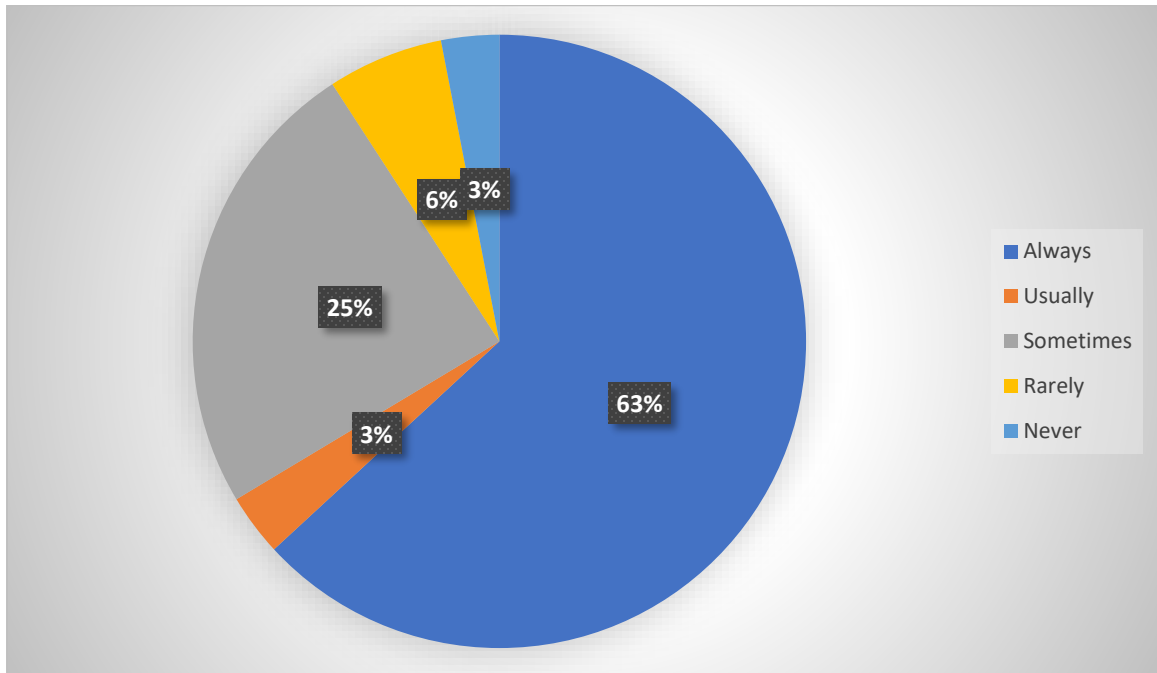


Figure 7: Child falls asleep alone in own bed

4.2.2 Bedtime resist going bed at bedtime

In this study it was found that about 46.1% (n=47) participants selecting never, 14.7% (n=15) participants selecting rarely, 30.4% (n=31) participants selecting sometimes, 4.9% (n=5) participants selecting usually and 3.9% (n=4) participants selecting always resist going bed at bedtime.

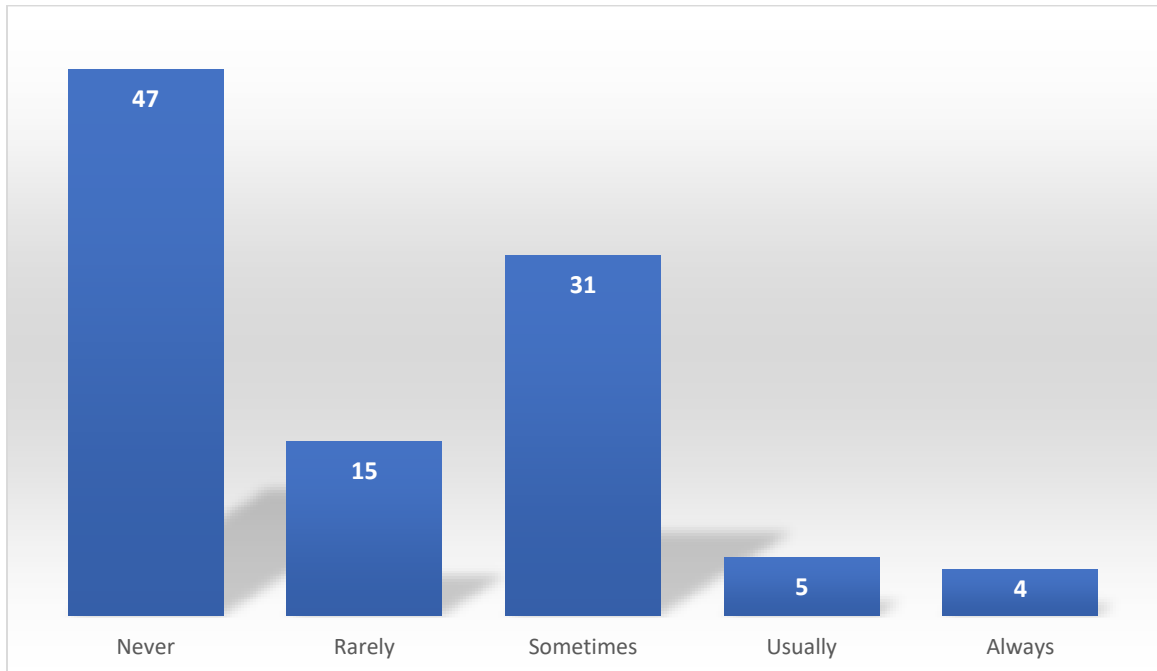


Figure 8: Resist going bed at bedtime

4.2.3 Bedtime afraid sleeping dark

In this study it was found that about 72% (n=74) participants selecting never, 7% (n=7) participants selecting rarely, 5% (n=5) participants selecting sometimes, 7% (n=7) participants selecting usually and 9% (n=9) participants selecting always afraid sleeping dark.

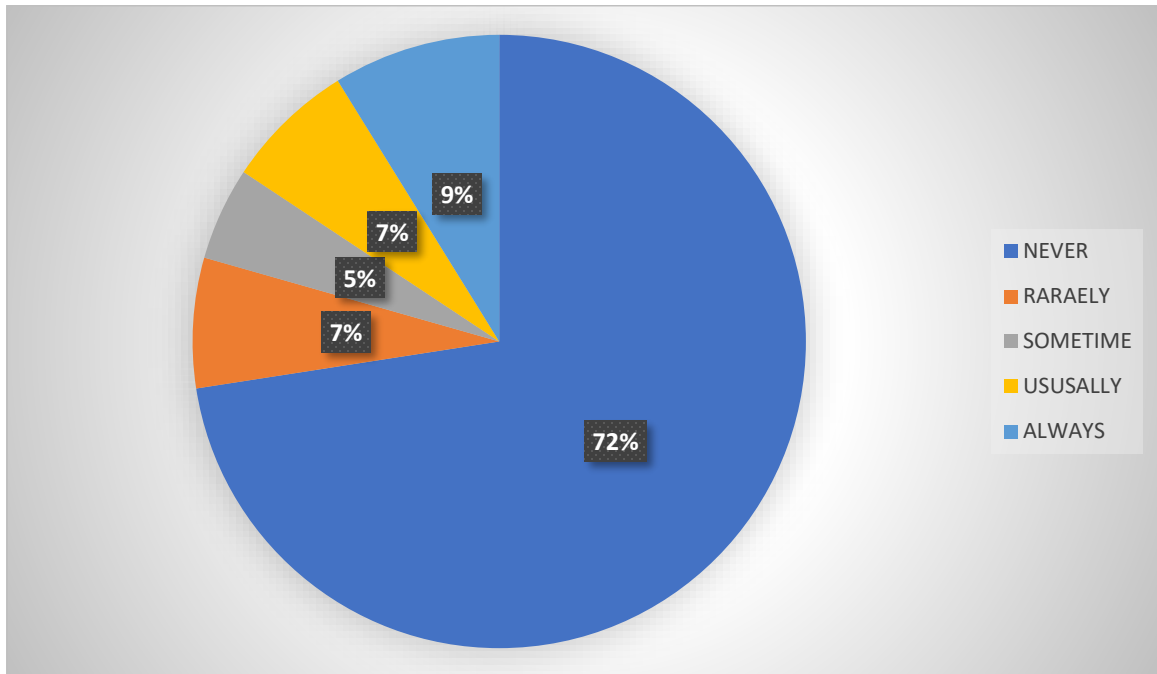


Figure 9: Afraid sleeping dark

4.2.4 Bedtime child falls asleep within 20 minutes after going to bed

In this study it was found that about 8.8% (n=9) participants selecting never, 66.7% (n=68) participants selecting rarely, 17.6% (n=18) participants selecting sometimes, 2% (n=2) participants selecting usually and 4.9% (n=5) participants selecting always falls asleep within 20 minutes after going to bed.

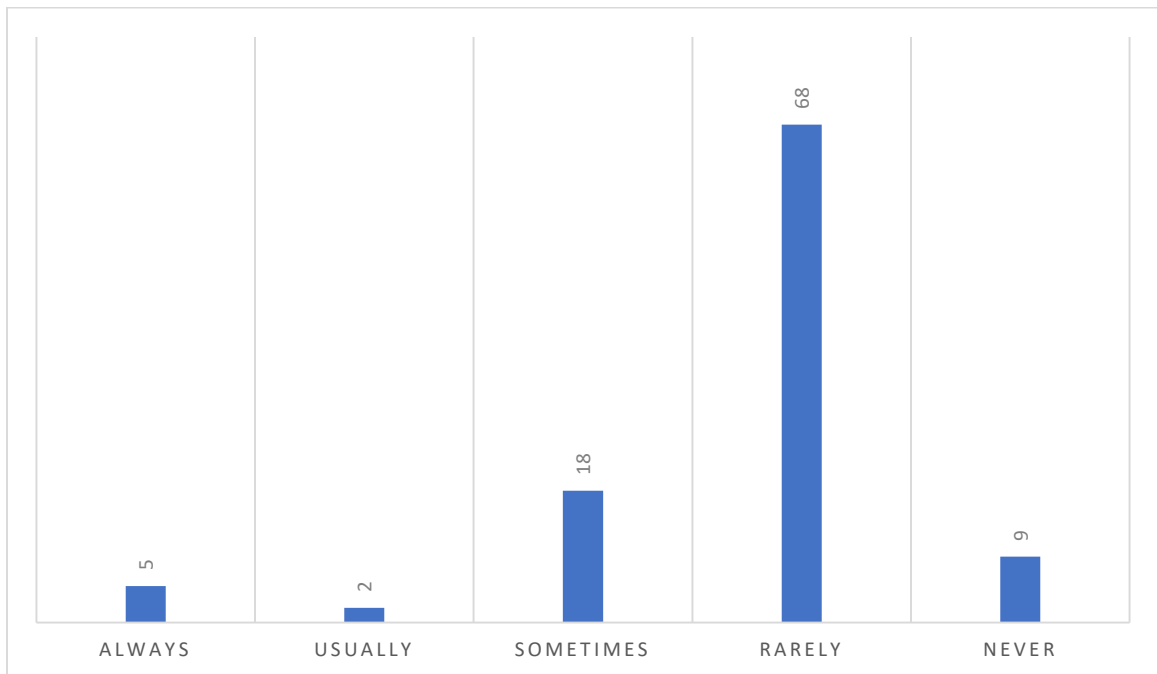


Figure 10: Child falls asleep within 20 minutes after going to bed

4.2.5 Bedtimes child falls asleep in parent's or sibling's bed

In this study it was found that about 34% (n=35) participants selecting never, 5% (n=5) participants selecting rarely, 42% (n=43) participants selecting sometimes, 15% (n=15) participants selecting usually and 4% (n=4) participants selecting always falls asleep in parent's or sibling's bed.

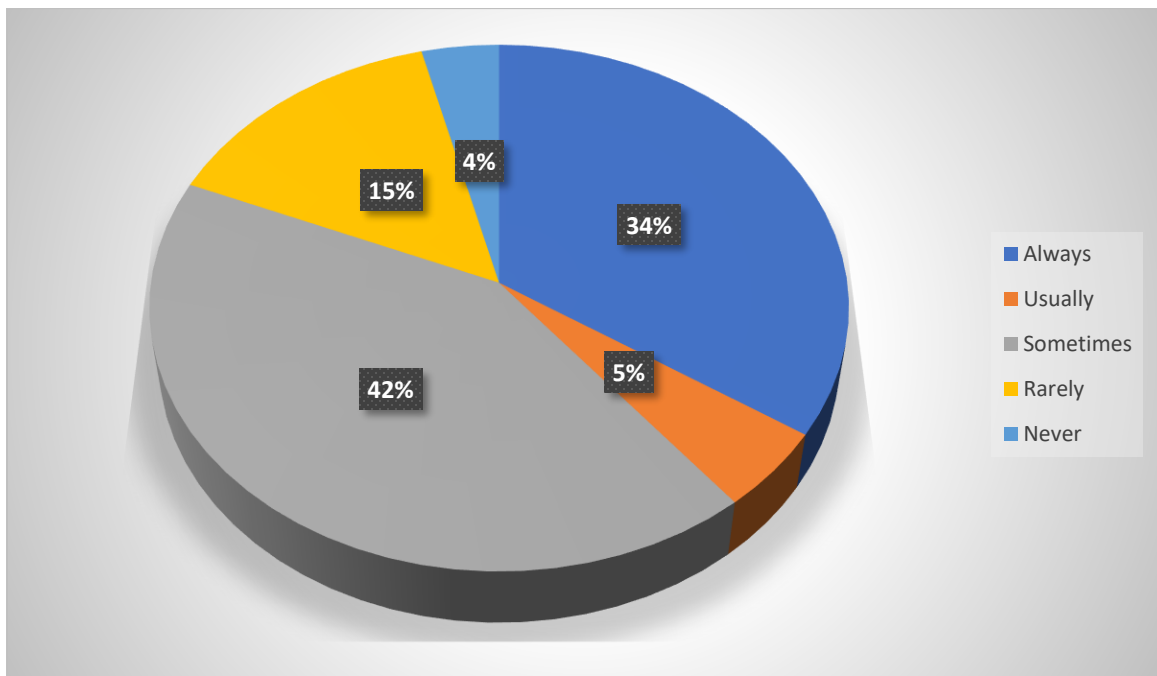


Figure 11: Child falls asleep in parent's or sibling's bed

4.2.5 Bedtime child goes to bed at the same time at night

In this study it was found that about 2.9% (n=3) participants selecting never, 71.6% (n=73) participants selecting rarely, 22.5% (n=23) participants selecting sometimes, 2% (n=2) participants selecting usually and 1% (n=1) participants selecting always child goes to bed at the same time at night.

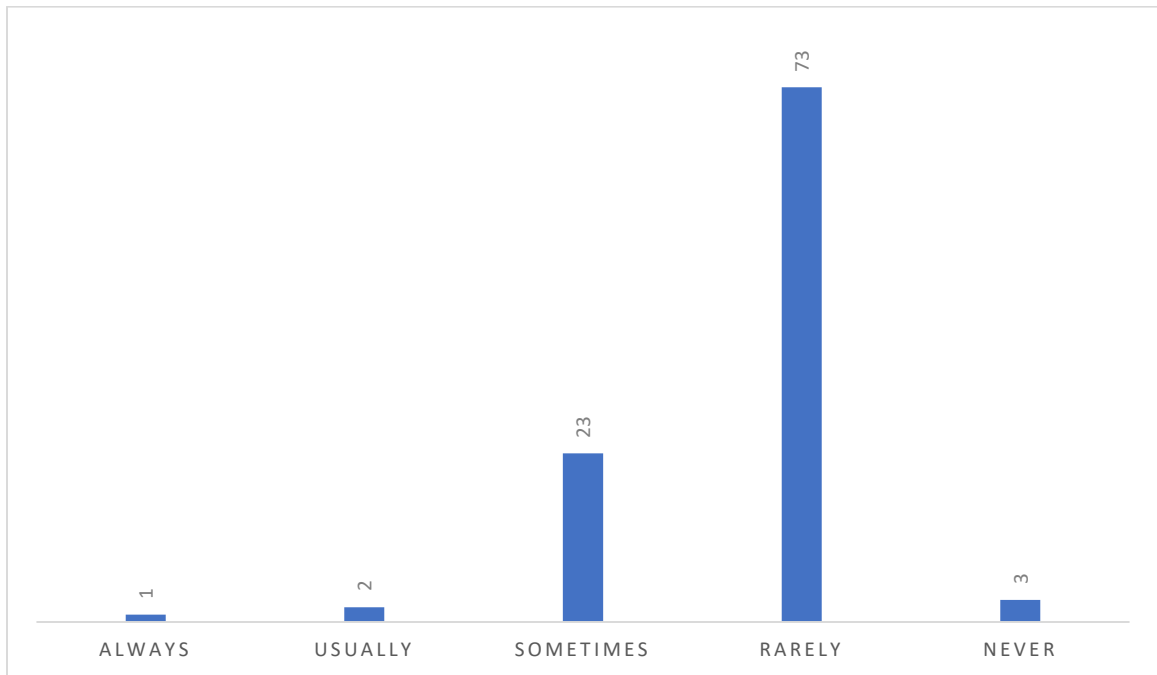


Figure 12: Child goes to bed at the same time at night

❖ Sleep behavior

4.2.6 Sleep behavior child awakens during the night

In this study it was found that about 1% (n=1) participants selecting never, 10% (n=11) participants selecting always, 14% (n=15) participants selecting usually, 50% (n=50) participants selecting sometimes and 25% (n=25) participants selecting rarely shows child awakens during the night.

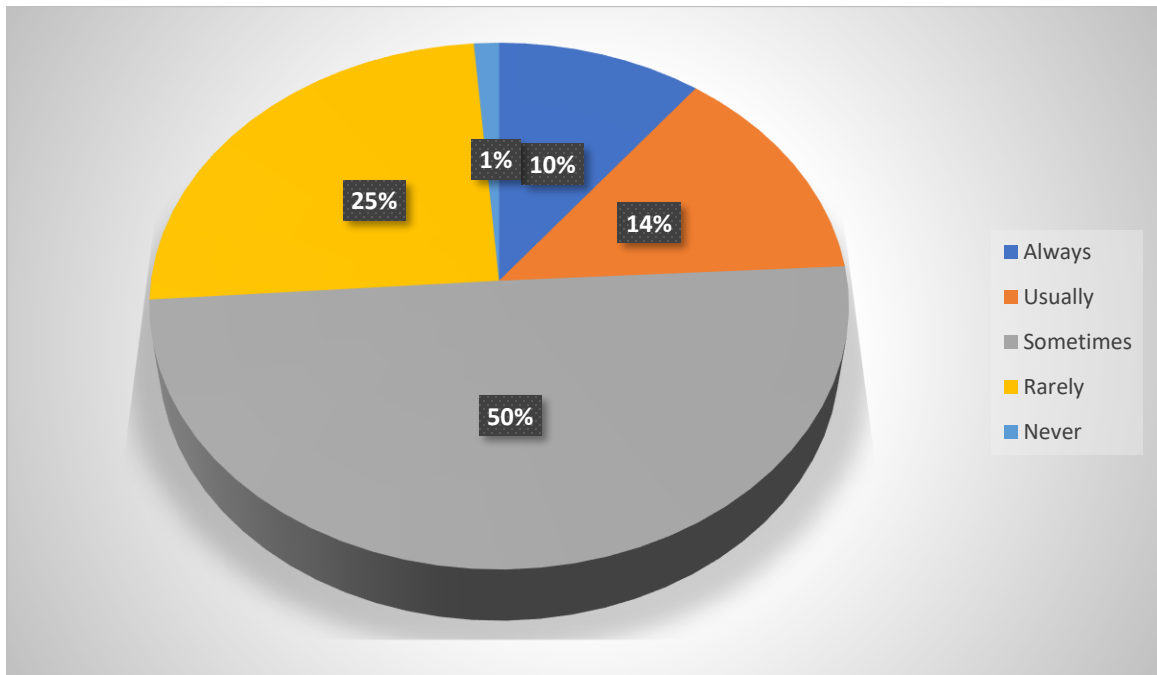


Figure 13: Child awakens during the night

4.2.7 Sleep behavior child sleep about the same amount each day

In this study it was found that about 3.9% (n=4) participants selecting never, 1% (n=1) participants selecting always, 29.4% (n=30) participants selecting usually, 61.8% (n=63) participants selecting sometimes and 3.9% (n=4) participants selecting rarely shows child sleep about the same amount each day.

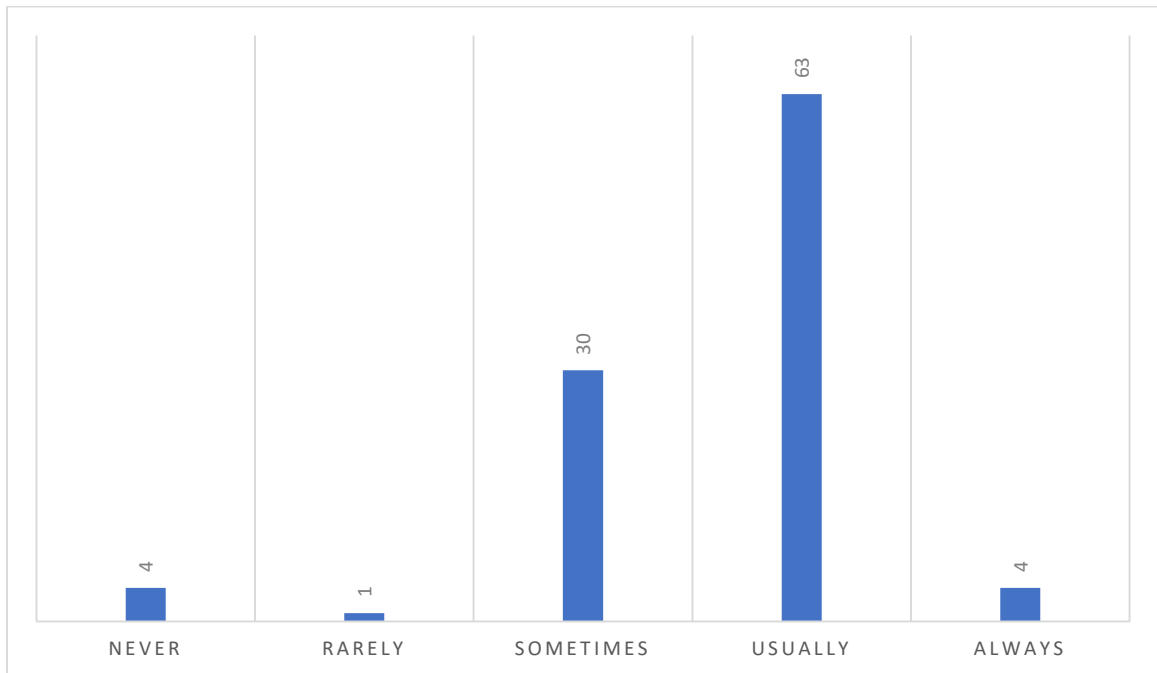


Figure 14: Child sleep about the same amount each day

4.2.8 Sleep behavior child moves bed during night

In this study it was found that about 8% (n=8) participants selecting never, 8% (n=8) participants selecting always, 18% (n=18) participants selecting usually, 55% (n=56) participants selecting sometimes and 11% (n=12) participants selecting rarely shows child moves bed during night.

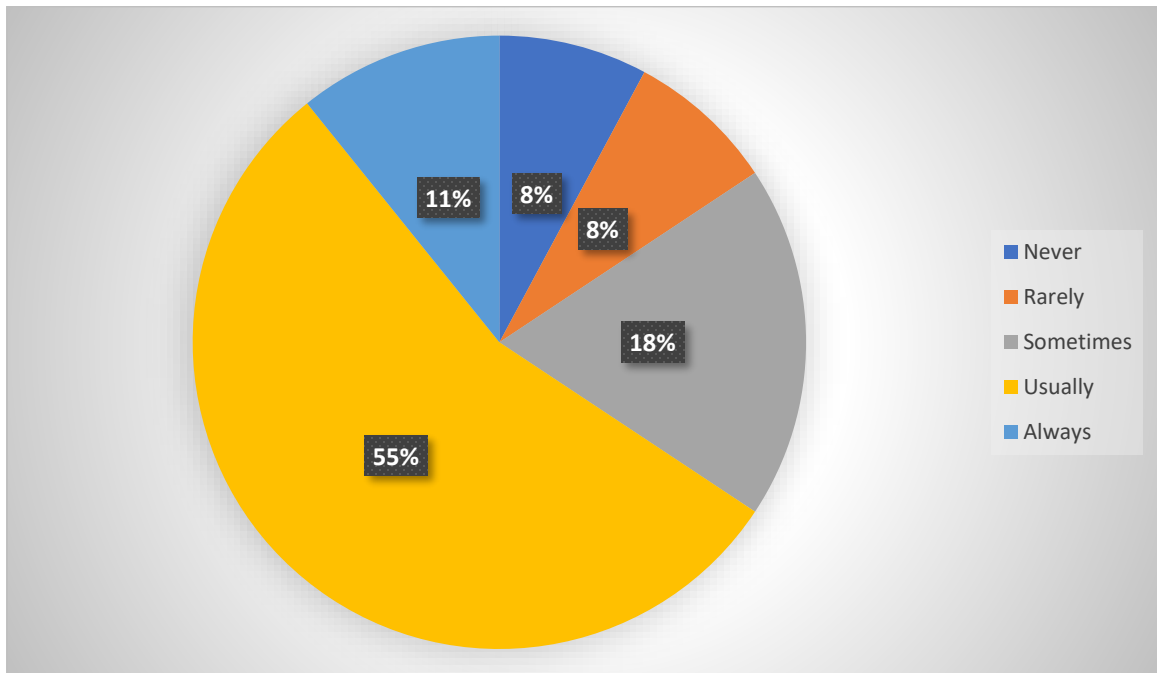


Figure 15: Child moves bed during night

4.2.9 Sleep behavior child grinds teeth during night

In this study it was found that about 79.4% (n=81) participants selecting never, 9.8% (n=10) participants selecting always, 3.9% (n=4) participants selecting usually, 5.9% (n=6) participants selecting sometimes and 1% (n=1) participants selecting rarely shows child grinds teeth during night.

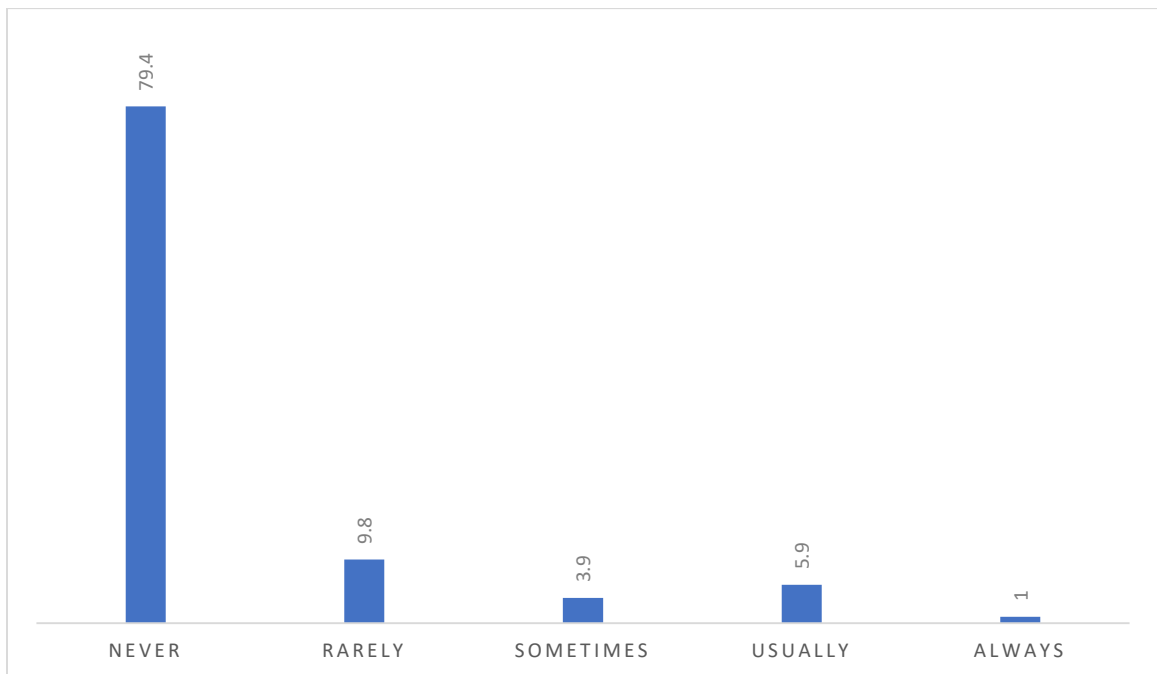


Figure16: Child grinds teeth during night

4.2.10 Sleep behavior child is restless during sleep

In this study it was found that about 32% (n=33) participants selecting never, 18% (n=18) participants selecting always, 36% (n=37) participants selecting usually, 11% (n=11) participants selecting sometimes and 3% (n=3) participants selecting rarely shows child is restless during sleep.

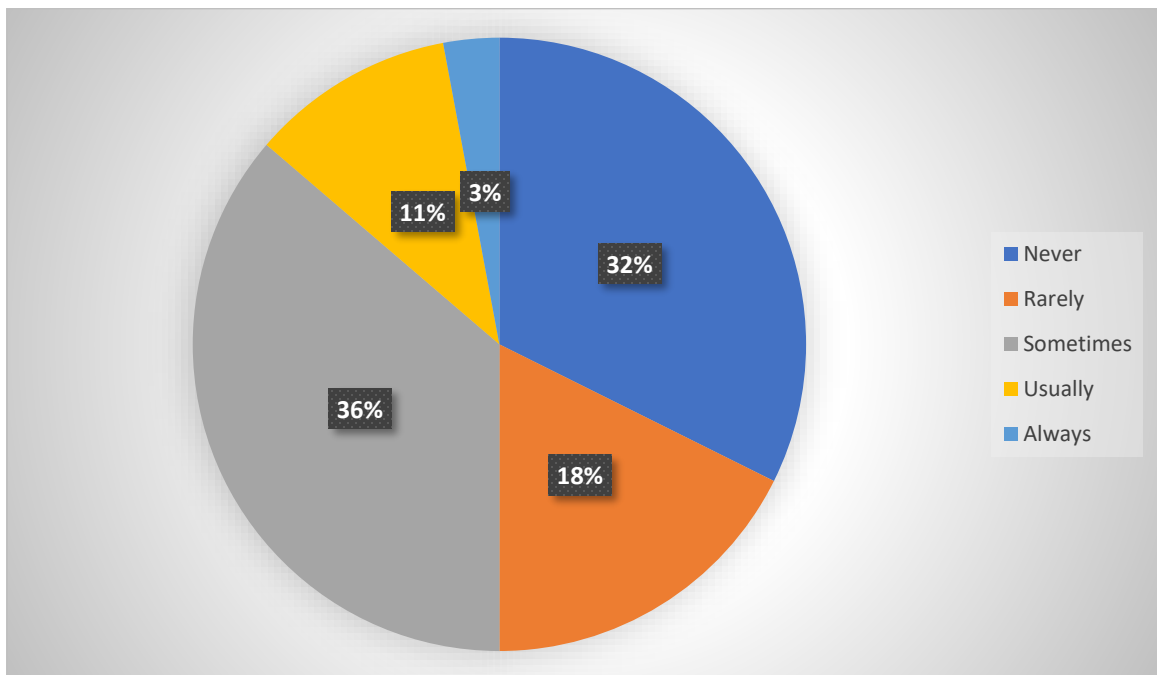


Figure 17: Child is restless during sleep

❖ Waking during the night

4.2.11 Waking during the night child wakes up more than once

Among 102 participants of this study found that about 3% (n=4) participants selecting never, 10% (n=10) participants selecting always, 20% (n=20) participants selecting usually, 24% (n=25) participants selecting sometimes and 43% (n=43) participants selecting rarely wakes up more than once.

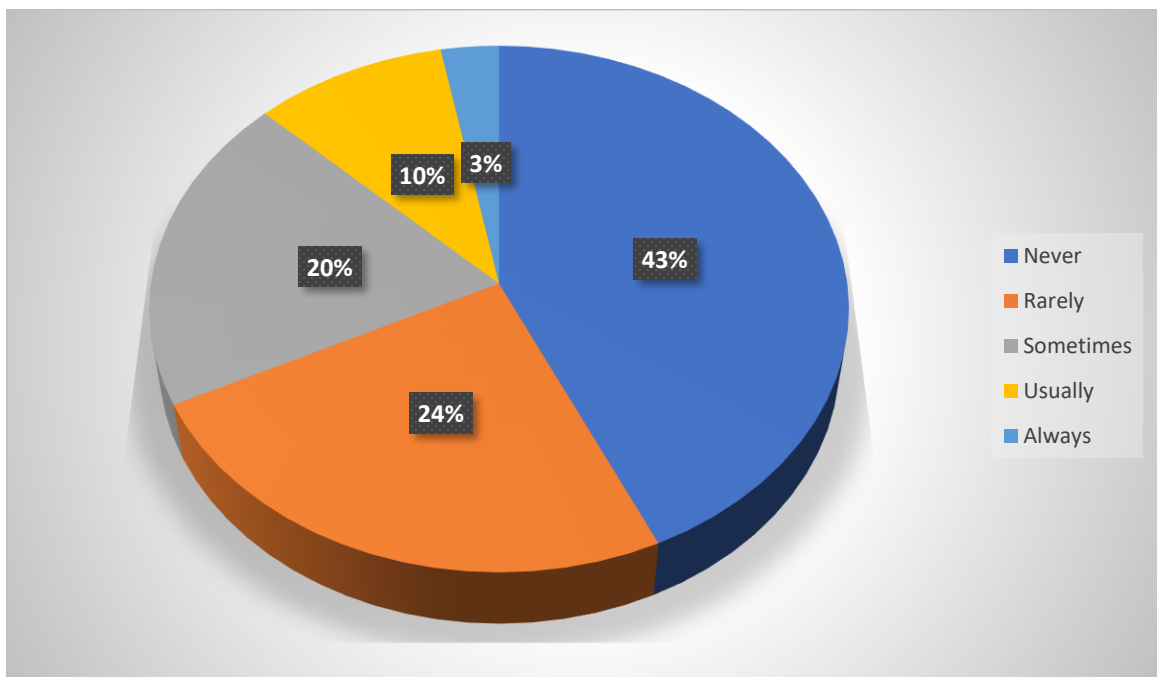


Figure 18: Child wakes up more than once

4.2.12 Waking during the night child wakes up once

In this study it was found that about 20.6% (n=21) participants selecting never, 34.3% (n=35) participants selecting always, 24.5% (n=25) participants selecting usually, 15.7% (n=16) participants selecting sometimes and 4.9% (n=5) participants selecting rarely shows child wakes up once.

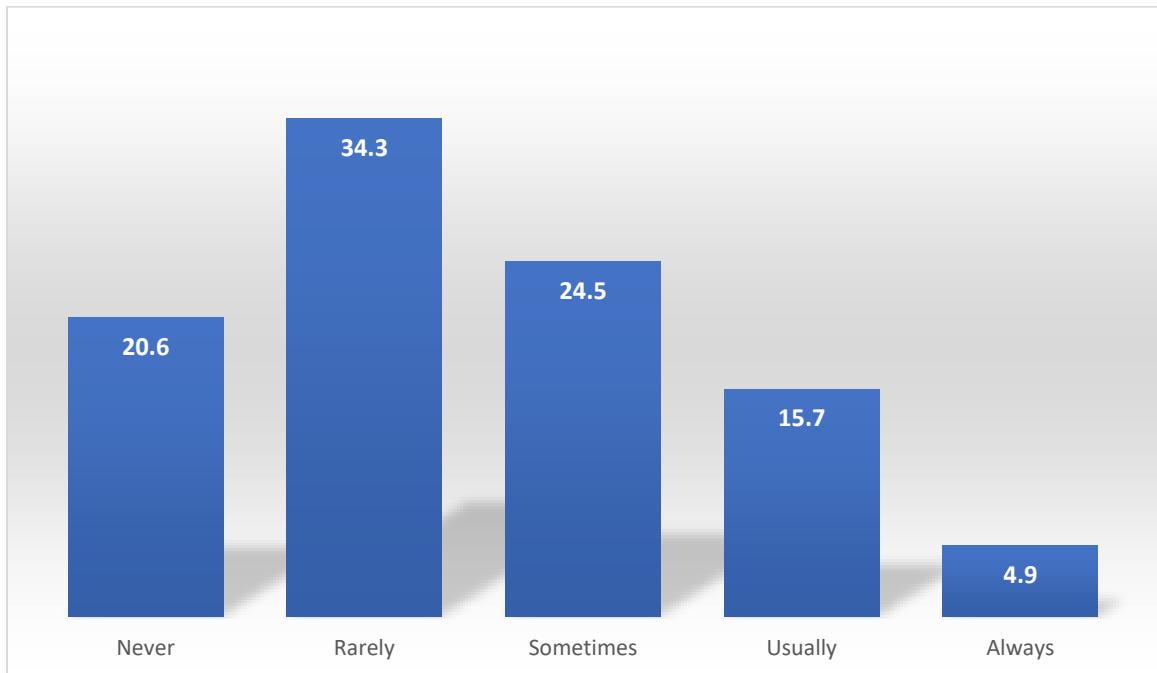


Figure 19: Child wakes up once

❖ Morning wake up

4.2.13 Morning wake up child falls asleep during activities

Among 102 participants of this study found that about 75.5% (n=77) participants selecting never, 12.7% (n=13) participants selecting always, 8.8% (n=9) participants selecting usually, 2% (n=2) participants selecting sometimes and 1% (n=1) participants selecting up child falls asleep during activities.

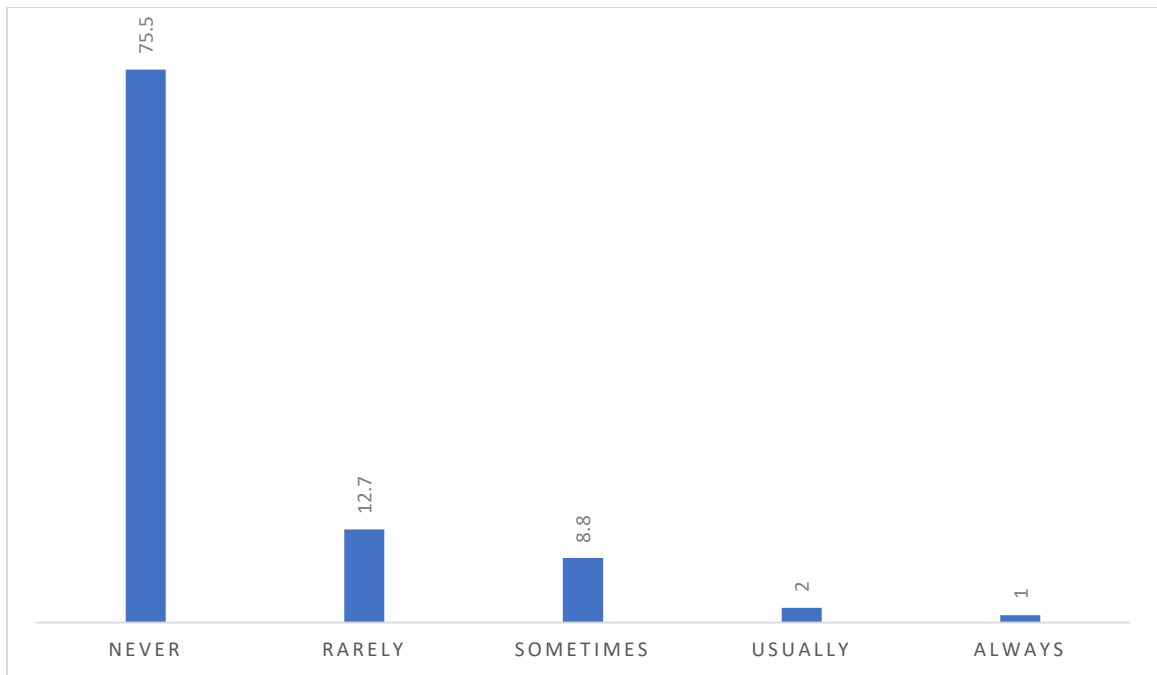


Figure 20: Child falls asleep during activities

4.2.14 Morning wake up child wakes up very early

In this study it was found that about 7% (n=7) participants selecting never, 6% (n=6) participants selecting always, 76% (n=78) participants selecting usually, 9% (n=9) participants selecting sometimes and 2% (n=2) participants selecting rarely shows child wakes up very early.

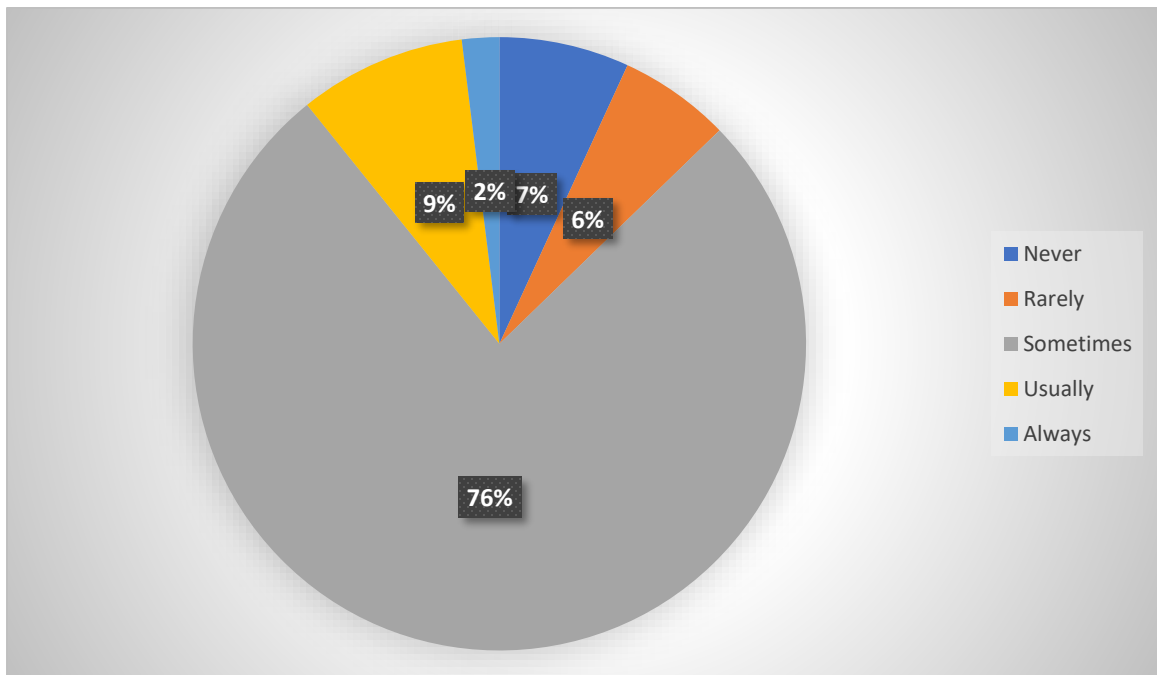


Figure 21: Child wakes up very early

4.2.15 Morning wake up child wakes up by himself

In this study it was found that about 4.9% (n=5) participants selecting never, 1% (n=1) participants selecting always, 42.2% (n=43) participants selecting usually, 36.3% (n=37) participants selecting sometimes and 15.7% (n=16) participants selecting rarely shows child wakes up by him or herself.

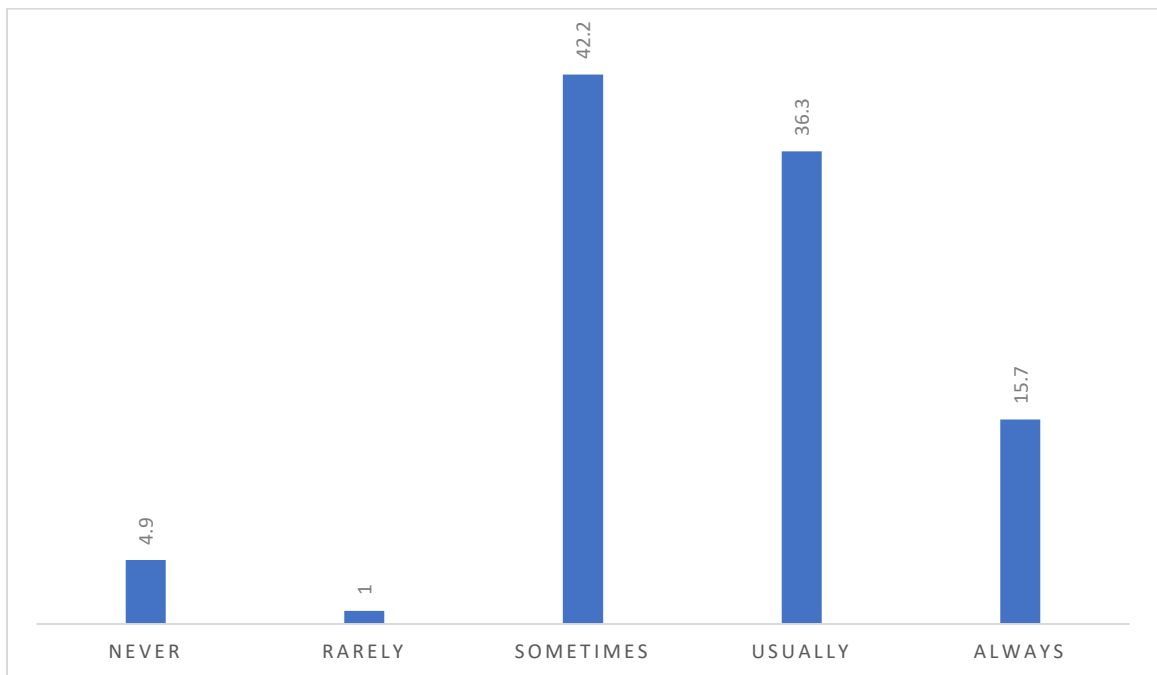


Figure 22: Child wakes up by himself

4.2.16 Morning wake up child seems tired during daytime

In this study it was found that about 26.5% (n=27) participants selecting never, 41.2% (n=42) participants selecting always, 25.5% (n=26) participants selecting usually, 2.9% (n=3) participants selecting sometimes and 3.9% (n=4) participants selecting rarely shows child seems tired during daytime.

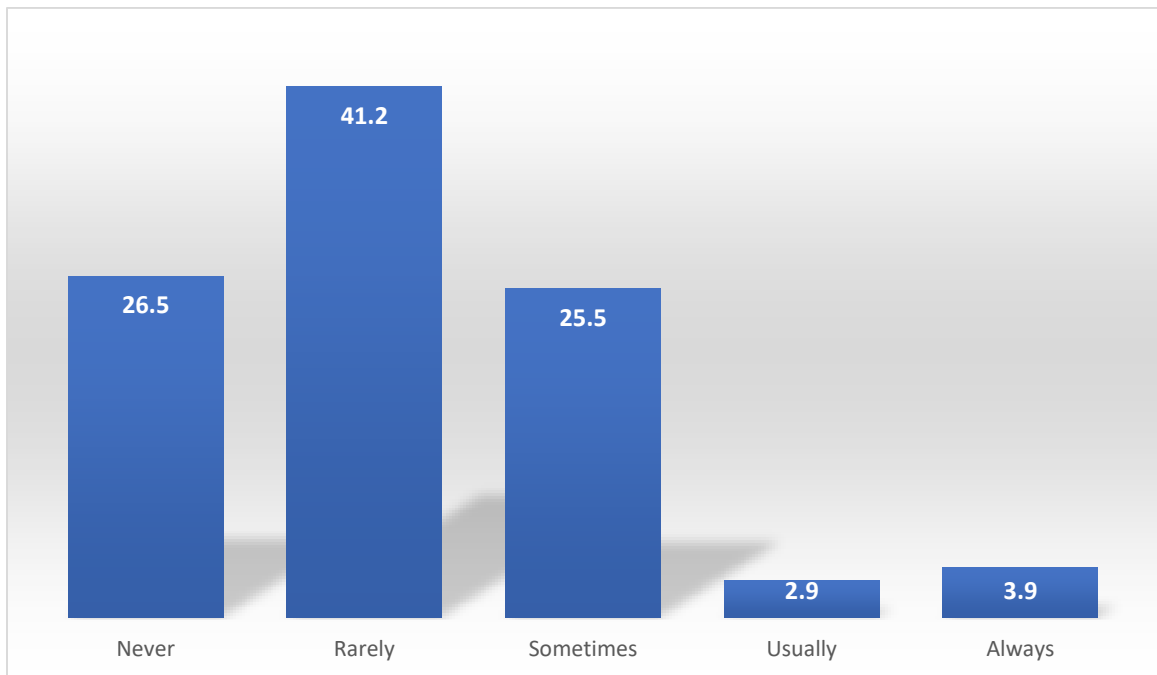


Figure 23: Child seems tired during daytime

4.3 Association between sociodemographic information and sleep disturbance

Sociodemographic variable	Sleep	Chi-Square value	Significance/ P value
Age	Sleep behavior	76.710	0.041
Occupation of respondent	Bedtime	58.879	0.039
	Morning wake up	41.671	0.056
Educational status	Bedtime	54.064	0.012
	Sleep behavior	35.934	0.050
Living area	Sleep behavior	15.936	0.031
	Waking during the night	14.944	0.054
Cousin marriage	Bedtime	16.452	0.009
Types of delivery	Bedtime	10.615	0.025
	Sleep behavior	10.873	0.020
Types of CP	Sleep behavior	24.652	0.008

Association of sociodemographic information with sleep disturbance:

One of the objective of this study was to examine an association between sociodemographic information and sleep disturbance. So in continuation of this, researcher have found out the p value (significant value) as well as test value by chi-square test.

Firstly, done an association in between CSHQ scores and independent variable than another association in between CPQOL categories and independent variable had done by researcher. After testing according to data type a significant value had been found there, significant value was found in between overall age of children and CSHQ scores (Sleep behavior) done by chi-square test that p value was 0.041 and the test value was 76.710. Overall occupation of respondent and CSHQ scores (Bedtime and morning wake up) were found significant value done by chi-square test (p value:0.039; p value:0.056) and the test value were (58.879, 41.671). Another significant value was found in between overall cousin marriage and CSHQ score (Bedtime) that p value was 0.009 and test values was 16.452. Overall types of CP and CSHQ scores (sleep behavior) was found significant value was 0.006 and the test value was 24.652. The significant values were found in between overall educational status and CSHQ score (Bedtime and sleep behavior) were found that significant values were (0.012, 0.050) and the test values were (54.064, 35.934). Another significant value was found in between overall types of delivery and CSHQ score (Bedtime and sleep behavior) were found that p values were (0.025,0.020) and test values were (10.615,10.873). Overall living area and CSHQ scores (Bedtime and waking during the night) were found significant value done by chi-square test that p values were (0.031, 0.054) and test values were (15.936, 14.944). Those types of values mentioned it was significant because if the ($p < 0.05$) it considered as significant.

4.4 Association between sociodemographic information and quality of life

Sociodemographic variable	QOL	Kruskal wallis/ Mann whitney value	Significance/ P value
Age	Family & friend	9.226 ^b	0.010
Gender	Family & friend	887.500 ^a	0.037
	Participation	861.000 ^a	0.024
	Special equipment	992.000 ^a	0.020
Occupation of respondent	Family and friend	17.133 ^b	0.009
		13.002 ^b	0.043
		26.017 ^b	0.000
	Participation	13.104 ^b	0.041
	Health	15.937 ^b	0.014
		20.407 ^b	0.002
		15.174 ^b	0.019
		19.578 ^b	0.003
	Special equipment	33.082 ^b	0.000
		14.932 ^b	0.021
		Pain & bother	14.036 ^b
			17.550 ^b
Educational status	Family & friend	11.564 ^b	0.041
	Special equipment	14.994 ^b	0.010
		67.212 ^b	0.000
		21.910 ^b	0.001
Living area	Family & friend	7.054 ^b	0.029
		6.935 ^b	0.031
	Health	6.570 ^b	0.037
Types of delivery	Family & friend	5.549 ^b	0.018
	Health	4.671 ^b	0.031
Types of CP	Family & friend	7.469 ^b	0.024
		6.629 ^b	0.036
	Participation	6.333 ^b	0.042

a= Mann whitney; b=Kruskal wallis

Association of sociodemographic information with quality of life:

Another association in between CPQOL and independent variable had been done by researcher an association between Children's age and CPQOL (Family and friend) are tested by Kruskal wallis and the test value (9.226) and p value (.010). Mann whitney is done to find out an association between gender and CPQOL (Family and friend, participation and special equipment) where test value (887.500, 861.000 and 992.000) and p value (0.037, 0.024 and 0.020). Occupation of respondent and CPQOL (Family and friend, Participation, Health, Special equipment and Pain and bother) are associated by kruskal wallis test (p value: 0.009; p value: 0.043; p value: 0.000; p value: 0.041; p value: 0.014; p value: 0.002; p value: 0.019; p value: 0.003; p value: 0.000; p value: 0.021; p value: 0.029; p value: 0.007) and the test values were (17.133, 13.002, 26.017, 13.104, 15.937, 20.407, 15.174, 19.578, 33.082, 14.932, 14.036 and 17.550). Kruskal wallis is also done to find out an association between educational status and CPQOL (Family and friend and special equipment) where test values were (11.564, 14.994, 67.212 and 21.910) and p value were (p value: 0.041; p value:0.010, p value: 0.000 and p value: 0.001). Living area and CPQOL (Family and friend and health) are associated by kruakal wallis test (p value: 0.029, p value: 0.031 and p value: 0.037) and the test values were (7.054, 6.935 and 6.571). Types of delivery and CPQOL (Family and friend and health) are associated by kruakal wallis test (p value: 0.018 and p value: 0.031) and the test values were (5.549and 4.671). Types of CP and CPQOL (Family and friend and health) are also associated by kruakal wallis test (p value: 0.024, p value: 0.036 and p value: 0.042) and the test values were (7.469, 6.629 and 6.333). All type of values mentioned it was significant because if the ($p < 0.05$) it considered as significant.

Cerebral Palsy is “a group of developmental disorders of movement and posture, causing activity limitation or disability imposed to disturbances occurring in the fetal or infant brain. The motor impairment may be associated by a seizure disorder and by impairment of sensation, cognition, communication and/or behavior and by further musculoskeletal problems.” Cerebral palsy is higher prevalence of disorder of initiation and maintenance of sleep, sleep–wake transition disorder, excessive sleepiness. It was hypothesized that presence of sleep problems would be associated with impaired QOL in children with CP (Samota et al., 2021).

In this study the responses were measured by the structured questionnaire including CSHQ and CPQOL. A descriptive and inferential statistical analysis have been directed to find out the result. In the descriptive section the categorical variables were measured in percentage and have been showed in different bar diagrams, pie charts and tables. In the inferential section, Mann whitney, Kruskal wallis and Chi-square test were conducted to find out the association between different dependent (sleep disturbance and quality of life) and independent variables (age, gender, occupation, educational status, type of delivery, types of CP etc).

In this study, result showed that sociodemographic information, sleep disturbance and quality of life according to CSHQ and CPQOL.

The purpose of this cross-sectional study is to investigate the sleep disturbance and quality of life. This study is modifiable as it is a cross-sectional study, and although it is considered an exploratory study, it does provide some relevant information regarding cerebral palsy and sleep disturbance and quality of life.

In this study, 102 participants of children with cerebral palsy are taken. In the case of age, the most participants were attended from 4-6 age groups. Among 102 of participants 69.6%(n=71) participants were in 4-6 age group, 25.5%(n=26) participants were in 7-9 age group and 4.9%(n=5) participants were in 10-12 age group.

A study conducted by Adiza et al. (2014) showed that thirty-five children (70%) were sharing their bed with their mothers. Bed-sharing had no association with pathological sleep in CP patients in their study. In this study, it was found that about 34% (n=35) participants selecting never, 5% (n=5) participants selecting rarely, 42% (n=43) participants selecting sometimes, 15% (n=15) participants selecting usually and 4% (n=4) participants selecting always falls asleep in parent's or sibling's bed.

Study was conducted by Kumar et al. (2016) with 81 participants with children of CP. In this study there was 56.79% male children they were 46 in number and 43.21% where female was 35 in number. Children's mean age was 6.57, SD±19. Education status of parents had three categories among them n=27 or 33.33% had completed their primary education, n=43 or 53.09% completed secondary education and n=11 or 13.58% had completed higher secondary education. On the other hand, in this study it included 102 participants of children with cerebral palsy male were n=64(63%) and number of female were n=38(37%), it showed most of the children of our study was male. Among 102 participants, parents' education level was below SSC (n= 2) 2%; S.S.C completed (n= 49) 48%; H.S.C completed(n=9)8.8%; Hon's completed (n=11) 10.8% and Masters completed (n= 10) 9.8%. In our study among 102 participants, govt. worker (n=5) 4.9%; businessman (n=19) 18.6%, labourer (n=1) 1%, unemployment (n=12) 11.8%, housewife (n=51) 50% and teacher (n=2) 2%. Urban area (n=34) 33%, semi-urban (n=17) 17% and rural (n=51) 50% were found in our study.

In addition, the monthly income of the parents of cerebral palsy children ranged from 5000-70000 taka. Most of the parent's (20%, n=20) monthly income 10000 taka. About 13% (n=13) of parent's monthly income is 20000 taka, 6% (n=6) of parent's monthly income ranged from 40000-50000 taka and 3% (n=3) of parent's monthly income is 6000 taka.

The result of the CSHQ scale showed that about 1% (n=1) participants selecting never goes to bed, 2% (n=2) participants selecting rarely goes to bed, 22.5% (n=23) participants selecting sometimes goes to bed, 71.6% (n=73) participants selecting usually goes to bed and 2.9% (n=3) participants selecting always goes to bed and also found that about 3.9% (n=4) participants selecting never, 1% (n=1) participants selecting always, 29.4% (n=30) participants selecting usually, 61.8% (n=63) participants selecting sometimes and 3.9%

(n=4) participants selecting rarely shows different sleep behavior and also found that about 75.5% (n=77) participants selecting never, 12.7% (n=13) participants selecting always, 8.8% (n=9) participants selecting usually, 2% (n=2) participants selecting sometimes and 1% (n=1) participants selecting rarely waking during the night.

In this study there was an association between sociodemographic information and sleep disturbance that tested by Chi-square test. Occupation of respondent and living area were found significant value with sleep disturbance (bedtime, sleep behavior, morning wake up and waking during the night) that the test value (58.879, 15.936, 41.671, 14.944) and p value (0.039,0.031, 0.056, 0.054). Another study conducted that Caregivers' variables, such as being single parents, bed-sharing, maternal employment, low socio-economic status, and sleep problems increased the frequency of children's sleep disorders and disorders of arousal. A child's sleep score was significantly positively associated with living in a single parent family, sleeping with parents and bed-sharing (Lelis et al., 2016)

A study included by Adiga et al. 2014 with forty-two children (84%) had spastic CP, five (10%) had mixed CP, and three (6%) had dyskinetic CP. Fifteen out of 42 with spastic CP were hemiplegic, 14 were diplegic, 4 were triplegic, and 9 were tetraplegic CP. On the other hand, this study it included seventy-nine children (79%) had spastic CP, nineteen children (19%) had dyskinetic CP and only two children (2%) had ataxic CP. Another study conducted that parental reports indicated that dyskinetic CP children presented significantly higher scores for sleepwake transition disorders and sleep hyperhidrosis than children with hemiplegia, quadriplegia, or diplegia.

A study conducted by Samota et al. (2021) showed that QOL of males was severely affected than females which was attributed to gender biased perception of disability by parents. In our study, we find same information. But another study showed that QOL of CP children was not affected by gender.

Study included that children have significantly higher QoL scores if their families have higher incomes, their parents have higher educational levels and are employed, or they live with both parents. In this study, socioeconomic determinants were associated weakly with QoL, as reported by the parents. They found that the risk of being in the lower quartile of

QoL in the parental relations domain increased with higher levels of parental education (Arnaud et al.2010).

On the other hand, in this study it included association between education of parents and quality of life such as, family and friend and special equipment were found significant value where the values were (11.564, 14.994, 67.212, 21.910) and p values were (0.041, 0.010, 0.000, 0.001).

A study conducted by Samota et al. (2021) had included education of parents was not significantly associated with QOL and QOL of CP children was not affected by gender. But in this study found that significant association of education of parents with quality of life and association between gender and quality of life were conducted significant value.

5.1 Limitations

Every research study inevitably has limitations due to the inherent challenge of achieving 100% accuracy. In the case of this particular study, several limitations and barriers should be taken into account when interpreting its results. The study had small sample size. Only 102 samples were taken in this study. Only 102 samples do not represent the condition of entire country's Cerebral palsy patients. If many samples were collected, it would be more productive. One of the main limitations was time. I had a limited amount of time to conduct the research, which prevented me from managing a big number of samples for the study. Only CRP, Savar, Dhaka was used for sample collection. The use of the parent proxy CP-QOL to evaluate child QOL is a significant restriction. If it was collected from other many institutes and rehabilitation center across the country, the result would be more reliable and appropriate and also give a clear impression about the sleep disturbance and quality of life among children with cerebral palsy in Bangladesh. The use of the parent proxy CP-QOL to evaluate child QOL is a significant restriction. It has been documented that children with CP typically score better on QOL than their parents. Non-significant results cannot be used as evidence of an absence of effect, which is another key limitation. Future studies could undertake a meta-analysis of individual patient data in addition to collecting data to achieve more accurate findings. The above mentioned topics were basically the limitation of this research. Since it was the researcher's first study project, the supervisor and the respected teachers should be willing to overlook any mistakes.

6.1 Conclusion

Cerebral palsy is an unexpected which has a lifelong effect on physical functioning and psychological wellbeing. Children with cerebral palsy needs greater assistance than normal child to perform their everyday tasks. Children with CP are more likely to develop and maintain sleep abnormalities, as well as disorders of the sleep-wake cycle, excessive daytime drowsiness, and arousal. It was predicted that presence of sleep problems would be associated with impaired QOL in children with CP. In addition, the study found a correlation between socio-demographic factors and bedtime information. According to the study's findings, there is a strong link between the socio-demographic factors and bedtime information by gender, and these results are consistent among research of high quality. Similarly, the study found a highly significant between sociodemographic information (education of parents) and quality of life (family and friend). Association between education of parents and quality of life (health) are also significant that is found.

Sociodemographic information (occupation of respondent) and sleep behavior (bedtime and morning wake up) were found highly association in this study. Association between cousin marriage, types of cerebral palsy and sleep disturbance (bedtime) were also significant that is found.

Our results confirm that sleep disorders are common in children with CP and that different factors, such as motor or cognitive impairment, sleep behavioral problems, bedtime, are important risk factors for the development of sleep disorders. Although none of these factors alone were associated with sleep disorders, the risk for developing abnormal patterns of sleep significantly increased with their presence. This relationship should be further explored in a larger sample to better understand how these factors influence each other and to establish possible causal relationships in more details. Furthermore, because we used screening questionnaire (CSHQ), a more structured in-depth interview or objective assessment may have taken more accurate information on both psychiatric and sleep disorders and allowed a more accurate diagnosis. A better understanding of these

mechanisms will enhance the opportunity to identify appropriate treatments to improve the well-being of the child and also the well-being of the family.

However, it is yet unknown exactly how best to treat these conditions in children with CP—whether it involves pharmaceutical therapy, behavioral intervention, or combination of these methods.

In children with neurodevelopmental impairment such as cerebral palsy, greater effort should be made to identify and manage sleep problems to help the child maximize his or her developmental potential. Further studies on diagnosis and treatment of sleep disorders in this population are greatly acquired to provide evidence-based guidelines useful to health care providers, parents, and children. Regular testing of children with CP for sleep disorders and appropriate treatment are suggested for a better quality of life.

6.2 Recommendation

The objective of this study was to assess the sleep disturbance and quality of life among children with cerebral palsy at CRP. After completing the research, the researcher found few recommendation. Some points to keep in mind that might be taken for the better accomplishment for further study. The main recommendations would be as follow:

To improve the study's generalizability, it is advisable to employ a random sampling technique instead of convenience sampling, thus enhancing the power of generalization. Should collect more samples for generating the findings and make more valid and reliable. To generalize the findings, sample should collect from different institutes and rehabilitation center in different districts of Bangladesh. Other measurement scales should be taken into consideration in order to provide an effective and efficient result in a generalized form. A larger sample size may strengthen the statistical significance of some of the results. As a treatment of sleep disorders in this population are greatly needed to provide evidence-based guidelines useful to health care providers. There were some limitations of this study mentioned at the relevant section and it is recommended to resolve those limitations during further research.

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APPENDIX

English Consent Form

(Please read out to the participants)

Greeting!

My name is Syeda Nasrin Begum. I am a 4th year student of B.Sc. in Physiotherapy program at Bangladesh Health Professions Institute (BHPI). For my study purpose I am conducting a study on cerebral palsy children and my study title is “Sleep disturbance and quality of life among children with cerebral palsy”. I would like to know about some personal information, other related information, as well as socioeconomic impact and sleep and quality of life regarding this study. This will take approximately 30 minutes. This is an academic study and will not be used for any other purpose. Your participation in the research will have no impact on your present or future treatment in Paediatric unit. Researcher will maintain confidentiality of all procedures. Your data will never be used without your permission. Your participation in this study is voluntary and you may withdraw yourself at any time during this study.

If you have any query about the study or your right as a participant, you may contact with me (01916330571) or my supervisor Prof. Md. Obaidul Haque, Vice Principal, BHPI (01712054026).

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

Yes.....No.....

Signature of the participant & Date....

Signature of the researcher & Date...

অনুমতিপত্র

শুভেচ্ছা!

আমি সৈয়দা নাসরিন বেগম, বিএসসি ৪র্থ বর্ষের (অনার্স) ঢাকা বিশ্ববিদ্যালয়ের মেডিসিন অনুষদের অধীনে বাংলাদেশ হেলথ প্রফেশনস ইনস্টিটিউটের (বিএইচপিআই) ফিজিওথেরাপির ছাত্রী। আমার ব্যাচেলর ডিগ্রী পেতে আমাকে একটি গবেষণা পরিচালনা করতে হবে এবং এটি আমার অধ্যয়নের একটি অংশ। অংশগ্রহণকারীদের নিম্নলিখিত পড়ার পরে গবেষণায় অংশগ্রহণের জন্য অনুরোধ করা হচ্ছে।

আমার গবেষণার শিরোনাম হল “সেলিব্রাল পলসিতে আক্রান্ত শিশুদের মধ্যে ঘুমের ব্যাঘাত এবং জীবনযাত্রার মান নির্ণয়।” এই গবেষণার মাধ্যমে আমি উক্ত সম্পর্কিত কারণগুলি অনুসন্ধান করব।

আমার গবেষণা প্রকল্প বাস্তবায়নের জন্য, আমাকে সিপি বাচ্চাদের পিতামাতা বা যত্নশীলদের কাছ থেকে ডাটা সংগ্রহ করতে হবে। অতএব, আপনি অধ্যয়নের জন্য আমার মূলবান বিষয় হতে পারেন এবং আমি আপনাকে আমার অধ্যয়নের অংশগ্রহণকারী হিসাবে অনুরোধ করতে চাই। আমি প্রতিশ্রুতিবদ্ধ যে অধ্যয়ন আপনার কাছে পোজ বা ক্ষতি করবে না।

আমি আপনাকে জানাতে চাই যে এটি একটি সম্পূর্ণরূপে একাডেমিক অধ্যয়ন এবং অন্য কোন উদ্দেশ্যে ব্যবহার করা হবেনা। আমি আশ্বাস দিচ্ছি যে সমস্ত তথ্য গোপন রাখা হবে। আপনার অংশগ্রহণ স্বেচ্ছায় হবে। আপনার কোনো দ্বিধা বা ঝুঁকি ছাড়াই অংশগ্রহণের ৭ দিনের সম্মতি প্রত্যাহার এবং অংশগ্রহণ বন্ধ করার অধিকার আছে।

অধ্যয়ন সম্পর্কে আপনার যদি কোন প্রশ্ন থাকে অংশগ্রহণকারী হিসাবে আপনি আমার সাথে (০১৯১৬৩৩০৫৭১) অথবা আমার সুপারভাইজার প্রফেসর মোঃ ওবায়দুল হক, ভাইস প্রিন্সিপাল, বিএইচ এর সাথে (০১৭১২০৫৪০২৬) যোগাযোগ করতে পারেন।

আমি শুরু করার আগে আপনার কোন প্রশ্ন আছে?

তাহলে ইন্টাভিউ নিয়ে এগিয়ে যেতে আমি কি আপনার সম্মতি পেতে পারি?

হ্যাঁ----- না-----

অংশগ্রহণকারীর স্বাক্ষর ----- তারিখ -----

গবেষকের স্বাক্ষর ----- তারিখ -----

Research Questionnaire (English)

Title: Sleep disturbance and quality of life among children with cerebral palsy.

Personal Information

Patient's ID:	
Patient's name:	
Father's name:	
Mother's name:	
Age:	
Gender:	
Address:	
Mobile no:	

Socio- demographic characteristics

Number of family members:	
Occupation of respondent (Father/ mother):	Govt. worker Businessman Farmer Labourer Unemployment Housewife Teacher Others
Educational status (Father/ Mother):	
Living area	Urban Semi urban Rural
Monthly expenses (In BDT):	
Cousin marriage:	Yes No
Types of delivery:	Normal vaginal delivery Cesarean section Forceps delivery
Type of CP (Diagnosed by Doctor/ Expert/Physiotherapist):	Spastic Athetoid Ataxic Mixed

CHILDREN'S SLEEP HABITS QUESTIONNAIRE

(ABBREVIATED)

The following statements are about your child's sleep habits and possible difficulties with sleep. Think about the past week in your life when you answer the questions. If last week was unusual for a specific reason, choose the most recent typical week. Unless noted, check Always if something occurs every night, Usually if it occurs 5 or 6 times a week, Sometimes if it occurs 2 to 4 times a week, Rarely if it occurs once a week, and Never if it occurs less than once a week.

BEDTIME

Write in your child's usual bedtime: Weeknights ____ : ____ am/pm

	7 Always	5-6 Usually	2-4 Sometimes	1 Rarely	0 Never
1. Child goes to bed at the same time at night.					
2. Child falls asleep within 20 minutes after going to bed.					
3. Child falls asleep alone in own bed.					
4. Child falls asleep in parent's or sibling's bed.					
5. Child falls asleep with rocking or rhythmic movements.					
6. Child needs special object to fall asleep (doll, special blanket, stuffed animal, etc.).					
7. Child needs parent in the room to fall asleep.					
8. Child resists going to bed at bedtime.					
9. Child is afraid of sleeping in the dark.					

SLEEP BEHAVIOR

Write in your child's usual amount of sleep each day: (____ hours and ____ minutes)

	7 Always	5-6 Usually	2-4 Sometimes	1 Rarely	0 Never

10. Child sleeps about the same amount each day.					
11. Child is restless and moves a lot during sleep.					
12. Child moves to someone else's bed during the night (parent, sibling, etc.).					
13. Child grinds teeth during sleep (your dentist may have told you this).					
14. Child snores loudly.					
15. Child awakens during the night and is sweating, screaming, and inconsolable.					

Write in the number of minutes the nap usually lasts: _____ minutes

WAKING DURING THE NIGHT

	7 Always	5-6 Usually	2-4 Someti mes	1 Rarely	0 Never
17. Child wakes up once during the night.					
18. Child wakes up more than once during the night.					

MORNING WAKE UP

Write in the time child usually wakes up in the morning: Weekdays ____: ____ am/pm

	7 Always	5-6 Usually	2-4 Sometimes	1 Rarely	0 Never
19. Child wakes up by him/herself.					
20. Child wakes up very early in the morning (or, earlier than necessary or desired).					
21. Child seems tired during the daytime.					
22. Child falls asleep while involved in activities.					

CPOOL (Cerebral Palsy Quality of Life)

We want to ask you some questions about how you think your child FEELS about aspects of their life such as family, friends, health and school. Each question begins with “How do you think your child FEELS about.....?” It is important for you to report how you believe your child feels. Sometimes it is difficult to know how your child is feeling. Please just try and answer as best as you can.

This questionnaire is measuring how your child feels, not what they can do

Family & Friends

Q. How do you think your child feels about ...

Very unhappy	Unhappy	Neither happy nor unhappy	Happy	Very Happy
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the way they get along with you?	1	2	3	4	5	6	7	8	9
----------------------------------	---	---	---	---	---	---	---	---	---

the way they get along with their brothers & sisters? OR <input type="checkbox"/> my child doesn't have any brothers or sisters	1	2	3	4	5	6	7	8	9
--	---	---	---	---	---	---	---	---	---

the way they get along with other children at preschool or school? (If your child attends more than one school, please think about the school where your child spends the most time). OR <input type="checkbox"/> my child does not attend preschool or school	1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---	---

the way they get along with other children outside preschool or school?	1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---	---

the way they get along with adults?	1	2	3	4	5	6	7	8	9
-------------------------------------	---	---	---	---	---	---	---	---	---

the way they get along with their teachers and/or carers?	1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---	---

Family & Friends

Q. How do you think your child feels about...

Very unhappy	Unhappy	Neither happy nor unhappy	Happy	Very Happy
--------------	---------	---------------------------	-------	------------

their ability to play on their own?	1	2	3	4	5	6	7	8	9
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their ability to play with friends?	1	2	3	4	5	6	7	8	9
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going out on trips with families?	1	2	3	4	5	6	7	8	9
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how they are accepted by their family?	1	2	3	4	5	6	7	8	9
--	---	---	---	---	---	---	---	---	---

how they are accepted by other children at preschool or school? (If your child attends more than one school, please think about the school where your child spends the most time). OR <input type="checkbox"/> my child does not attend preschool or school	1	2	3	4	5	6	7	8	9
--	---	---	---	---	---	---	---	---	---

how they are accepted by other children outside of preschool or school?	1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---	---

how they are accepted by adults?	1	2	3	4	5	6	7	8	9
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how they are accepted by people in general?	1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---	---

being able to do things they want to do?	1	2	3	4	5	6	7	8	9
--	---	---	---	---	---	---	---	---	---

Participation

Q. How do you think your child feels about...

Very unhappy	Unhappy	Neither happy nor unhappy	Happy	Very Happy
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their ability to participate at preschool or school? (If your child attends more than one school, please think	1	2	3	4	5	6	7	8	9
--	---	---	---	---	---	---	---	---	---

about the school where your child spends the most time). OR <input type="checkbox"/> my child does not attend preschool or school									
--	--	--	--	--	--	--	--	--	--

their ability to participate in recreational activities?	1	2	3	4	5	6	7	8	9
--	---	---	---	---	---	---	---	---	---

their ability to participate in sporting activities? (This question is asking how your child feels about their ability to participate in sport, not whether they can participate).	1	2	3	4	5	6	7	8	9
--	---	---	---	---	---	---	---	---	---

their ability to participate in social events outside of preschool or school?	1	2	3	4	5	6	7	8	9
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their ability to participate in their community?	1	2	3	4	5	6	7	8	9
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Communication

Q. How do you think your child feels about...

Very unhappy	Unhappy	Neither happy nor unhappy	Happy	Very Happy
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the way they communicate with people they know well	1	2	3	4	5	6	7	8	9
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the way they communicate with people they don't know well	1	2	3	4	5	6	7	8	9
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the way other people communicate with them?	1	2	3	4	5	6	7	8	9
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Health

their physical health?	1	2	3	4	5	6	7	8	9
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the way they get around?	1	2	3	4	5	6	7	8	9
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how they sleep?	1	2	3	4	5	6	7	8	9
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the way they look?	1	2	3	4	5	6	7	8	9
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their ability to keep up academically with their peers?	1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---	---

their ability to keep up physically with their peers?	1	2	3	4	5	6	7	8	9
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Special Equipment

Q. How do you think your child feels about...

Very unhappy	Unhappy	Neither happy nor unhappy	Happy	Very Happy
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the special equipment they have at home (e.g. special seating, standing frames, wheelchairs, walkers)? OR <input type="checkbox"/> my child does not have any special equipment at home	1	2	3	4	5	6	7	8	9
--	---	---	---	---	---	---	---	---	---

the special equipment they have at their school? (e.g. special seating, standing frames, wheelchairs, walkers)? OR <input type="checkbox"/> my child does not have any special equipment at home	1	2	3	4	5	6	7	8	9
---	---	---	---	---	---	---	---	---	---

the special equipment they have at their school? (e.g. special seating, standing frames, wheelchairs, walkers)? OR <input type="checkbox"/> my child does not have any special equipment at school	1	2	3	4	5	6	7	8	9
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Pain and Bother

The next few questions ask about things that may bother your child.

Not bothered at all

Very bothe red

Is your child bothered by hospital visits?	1	2	3	4	5	6	7	8	9
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Is your child bothered when they miss school for health reasons?	1	2	3	4	5	6	7	8	9
--	---	---	---	---	---	---	---	---	---

Is your child bothered by being handled by other people?	1	2	3	4	5	6	7	8	9
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Never	Rarely	Sometimes	Often	Always
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Does your child worry about who will take care of them in the future?	1	2	3	4	5
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প্রশ্নপত্র

শিরোনাম: সেরিব্রাল পলসিতে আক্রান্ত শিশুদের মধ্যে ঘুমের ব্যাঘাত এবং জীবনযাত্রার মান নির্ণয়

পার্ট -১: ব্যক্তিগত তথ্য

রোগীর আইডি:	
রোগীর নাম:	
বাবার নাম:	
মায়ের নাম:	
বয়স:	
লিঙ্গ:	
ঠিকানা:	
মোবাইল নাম্বার:	

পার্ট -২ : সামাজিক- জনসংখ্যাগত তথ্য

পরিবারের সদস্য সংখ্যা:	
উত্তরদাতার পেশা (পিতা/মা):	১. সরকার কর্মী ২. ব্যবসায়ী ৩. শিক্ষক ৪. গৃহিণী ৫. বেকারত্ব ৬. অন্যান্য
শিক্ষাগত অবস্থা (পিতা/মা):	
আবাসস্থল:	১. শহর ২. আধা-শহরে ৩. গ্রামীণ
মাসিক খরচ (টাকাতে):	
নিকট আত্মীয়ের সাথে বিবাহ:	১. হ্যাঁ ২. না
প্রসবের ধরণ:	১. নরমাল ভেজাইনাল ডেলিভারি ২. সিজারিয়ান বিভাগ ৩. ফর্সেপস্ ডেলিভারি
সেরিব্রাল পালসির ধরন:	১. স্পাস্টিক ২. অ্যাথ্যাটয়েড ৩. অ্যাটাক্সিক ৪. মিশ্রিত

পার্ট -৩: বাচ্চাদের ঘুমের অভ্যাস সংক্রান্ত প্রশ্নাবলী

নিম্নলিখিত বিবৃতিগুলি আপনার সন্তানের ঘুমের অভ্যাস এবং ঘুমের সাথে সম্ভাব্য অসুবিধা সম্পর্কে। আপনি যখন প্রশ্নের উত্তর দিবেন তখন আপনার জীবনের গত সপ্তাহের কথা চিন্তা করুন। যদি গত সপ্তাহটি নির্দিষ্ট কারণে অস্বাভাবিক ছিল বলে মনে হয়, তবে অতি সাম্প্রতিক সাধারণ সপ্তাহের কথা চিন্তা করুন। যদি প্রতি রাতে কোনো কিছু ঘটে থাকে তখন **সর্বদা** তে, যদি এটি সপ্তাহে ৫ বা ৬ বার ঘটে থাকে তখন **সাধারণত**, যদি এটি সপ্তাহে ২ থেকে ৪ বার ঘটে থাকে তখন **মাঝে মাঝে** তে, যদি এটি সপ্তাহে একবার ঘটে থাকে তখন **কদাচিৎ**, এবং যদি এটি সপ্তাহে একবারও না ঘটে তখন **কখনই না** তে টিক চিহ্ন দিবেন।

শোবার সময়

আপনার সন্তানের স্বাভাবিক শোবার সময় লিখুন: সপ্তাহের রাত -----: ----- এএম/পিএম

	৭ সর্বদা	৫-৬ সাধারণত	২-৪ মাঝে মাঝে	১ কদাচিৎ	০ কখনই না
১. শিশু প্রতি রাতে একই সময়ে বিছানায় যায়।					
২. বিছানায় যাওয়ার ২০ মিনিটে মধ্যে শিশু ঘুমিয়ে পড়ে।					
৩. শিশু নিজের বিছানায় একা ঘুমিয়ে পড়ে।					
৪. শিশু পিতামাতার বা ভাইবোনের বিছানায় ঘুমিয়ে পড়ে।					
৫. শিশু দোলনা বা ছন্দবদ্ধ আন্দোলনে ঘুমিয়ে পড়ে।					
৬. ঘুমিয়ে পড়ার জন্য শিশুর বিশেষ বস্তুর প্রয়োজন (পুতুল, বিশেষ কম্বল, স্টাফ পশু, ইত্যাদি)।					
৭. শিশুর ঘুমিয়ে পড়ার জন্য ঘরে পিতামাতার প্রয়োজন।					
৮. শিশু শোবার সময় বিছানায় যেতে বাধা দেয়।					
৯. শিশু অন্ধকারে ঘুমাতে ভয় পায়।					

ঘুমের আচরণ

প্রতিদিন আপনার সন্তানের ঘুমের স্বাভাবিক পরিমাণ লিখুন : (_____ ঘন্টা _____ মিনিট)

	৭ সর্বদা	৫-৬ সাধারণত	২-৪ মাঝে মাঝে	১ কদাচিৎ	০ কখনই না
১০. শিশু প্রতিদিন প্রায় একই পরিমাণ ঘুমায়।					
১১. শিশু অস্থির এবং ঘুমের সময় অনেক নড়াচড়া করে।					
১২. শিশু রাতে অন্য কারো বিছানায় চলে যায় (পিতামাতা, ভাইবোন, ইত্যাদি)।					
১৩. শিশু ঘুমের সময় দাঁত পিষে (আপনার ডেন্টিস্ট হয়তো আপনাকে এটা বলেছে)।					
১৪. শিশু জোরে নাক ডাকে।					
১৫. শিশু রাতে জেগে ওঠে এবং ঘামে, চিৎকার করে এবং অস্থি থাকে।					
১৬. শিশু দিনের বেলা ঘুমায়।					
নিম্ন সাধারণত কত মিনিট স্থায়ী হয় তা	লিখুন: -----মিনিট				

রাত জেগে উঠা

	৭ সর্বদা	৫-৬ সাধারণত	২-৪ মাঝে মাঝে	১ কদাচিৎ	০ কখনই না
১৭. শিশু রাতে একবার জেগে ওঠে।					
১৮. শিশু রাতে একাধিকবার জেগে ওঠে।					

সকালে ঘুম থেকে উঠা

শিশু সাধারণত সকালে ঘুম থেকে ওঠার সময় লিখুন: সপ্তাহের রাত -----: ----- এএম/পিএম

১৯. শিশু নিজে থেকেই জেগে ওঠে।					
২০. শিশু খুব সকালে ঘুম থেকে ওঠে (বা, প্রয়োজনীয় বা কাঙ্ক্ষিতের চেয়ে আগে)।					
২১. শিশু দিনের বেলায় ক্লান্ত মনে হয়।					
২২. কার্যকলাপে জড়িত থাকার সময় শিশু ঘুমিয়ে পড়ে।					

পার্ট -৪ : শিশুদের জীবন যাত্রার মান সংক্রান্ত প্রশ্নাবলী:

পরিবার এবং বন্ধু

প্রশ্ন: আপনার সন্তানের অনুভূতি কেমন মনে হয়...

খুবই অসুখী	অসুখী	সুখী বা অসুখী না	সুখী	খুব সুখী
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যেভাবে তারা সাধারণভাবে মানুষের সাথে মিলিত হয়?	১	২	৩	৪	৫	৬	৭	৮	৯
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যেভাবে তারা আপনার সাথে মিলিত হয়?	১	২	৩	৪	৫	৬	৭	৮	৯
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যেভাবে তারা তাদের ভাই ও বোনদের সাথে মিলিত হয়?	১	২	৩	৪	৫	৬	৭	৮	৯
অথবা <input type="checkbox"/> আমার সন্তানের কোন ভাই বা বোন নেই									

যেভাবে তারা অন্যান্য শিশুদের সাথে মিলিত হয় প্রি-স্কুল বা স্কুলে? (যদি আপনার সন্তান একাধিক স্কুলে পড়ে, তাহলে অনুগ্রহ করে সেই স্কুলের কথা চিন্তা করুন যেখানে আপনার সন্তান সবচেয়ে বেশি সময় কাটায়)	১	২	৩	৪	৫	৬	৭	৮	৯
অথবা <input type="checkbox"/> আমার সন্তান প্রি-স্কুল বা স্কুলে যায় না									

যেভাবে তারা বাইরে অন্য বাচ্চাদের সাথে মিলিত হয় প্রিস্কুল বা স্কুলে?	১	২	৩	৪	৫	৬	৭	৮	৯
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যেভাবে তারা প্রাপ্তবয়স্কদের সাথে মিলিত হয়?	১	২	৩	৪	৫	৬	৭	৮	৯
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তারা তাদের শিক্ষক এবং/অথবা যত্নশীলদের সাথে কীভাবে মিলিত হয়?	১	২	৩	৪	৫	৬	৭	৮	৯
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পরিবার এবং বন্ধু

প্রশ্ন: আপনার সন্তানের অনুভূতি কেমন মনে হয়..

খুবই অসুখী	অসুখী	সুখী বা অসুখী না	সুখী	খুব সুখী
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তাদের নিজস্ব খেলার ক্ষমতা?	১	২	৩	৪	৫	৬	৭	৮	৯
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তাদের বন্ধুদের সাথে খেলার ক্ষমতা?	১	২	৩	৪	৫	৬	৭	৮	৯
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পরিবারের সাথে বেড়াতে যাচ্ছেন?	১	২	৩	৪	৫	৬	৭	৮	৯
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তারা তাদের পরিবারের দ্বারা কেমন গৃহীত হয়?	১	২	৩	৪	৫	৬	৭	৮	৯
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কিভাবে তাদের গ্রহণ করা হয় প্রিস্কুল বা স্কুলে অন্যান্য শিশুদের দ্বারা? (যদি আপনার সন্তান একাধিক স্কুলে পড়ে, তাহলে অনুগ্রহ করে আপনার সন্তানের সেই স্কুলের কথা চিন্তা করুন যেখানে আপনার সন্তান সবচেয়ে বেশি সময় কাটায়) অথবা <input type="checkbox"/> আমার সন্তান প্রি-স্কুল বা স্কুলে যায় না	১	২	৩	৪	৫	৬	৭	৮	৯
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কিভাবে তাদের প্রিন্সুল বা স্কুলের বাইরে অন্যান্য শিশুদের দ্বারা গ্রহণ করা হয়?	১	২	৩	৪	৫	৬	৭	৮	৯
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কিভাবে তারা প্রাপ্তবয়স্কদের দ্বারা গৃহীত হয়?	১	২	৩	৪	৫	৬	৭	৮	৯
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তারা কিভাবে সাধারণ মানুষ দ্বারা গৃহীত হয় ?	১	২	৩	৪	৫	৬	৭	৮	৯
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তারা যা করতে চায় তা করতে সক্ষম হচ্ছে?	১	২	৩	৪	৫	৬	৭	৮	৯
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অংশগ্রহণ

প্রশ্ন: আপনার সন্তানের অনুভূতি কেমন মনে হয়...

খুবই অসুখী	অসুখী	সুখী বা অসুখী না	সুখী	খুব সুখী
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প্রিন্সুল বা স্কুলে তাদের অংশগ্রহণের ক্ষমতা? (যদি আপনার সন্তান একাধিক স্কুলে পড়ে, তাহলে অনুগ্রহ করে আপনার সন্তানের সেই স্কুলের কথা চিন্তা করুন যেখানে আপনার সন্তান সবচেয়ে বেশি সময় কাটায়) অথবা <input type="checkbox"/> আমার সন্তান প্রিন্সুল বা স্কুলে যায় না	১	২	৩	৪	৫	৬	৭	৮	৯
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তাদের বিনোদনমূলক কর্মকান্ডে অংশগ্রহণ করার ক্ষমতা?	১	২	৩	৪	৫	৬	৭	৮	৯
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তাদের ক্রীড়া কার্যক্রমে অংশগ্রহণ করার ক্ষমতা? (এই প্রশ্নটি জিজ্ঞাসা করছে যে আপনার সন্তান খেলাধুলায় অংশগ্রহণ করার ক্ষমতা সম্পর্কে কেমন অনুভব করে, তারা অংশগ্রহণ করতে পারে কিনা)।	১	২	৩	৪	৫	৬	৭	৮	৯
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তাদের প্রিন্সুল বা স্কুলের বাইরে সামাজিক ইভেন্টে অংশগ্রহণ করার ক্ষমতা?	১	২	৩	৪	৫	৬	৭	৮	৯
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তাদের সম্প্রদায়ে তাদের অংশগ্রহণ করার ক্ষমতা?	১	২	৩	৪	৫	৬	৭	৮	৯
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যোগাযোগ

প্রশ্ন: আপনার সন্তানের অনুভূতি কেমন মনে হয়...

খুবই অসুখী	অসুখী	সুখী বা অসুখী না	সুখী	খুব সুখী
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যেভাবে তারা ভালো করে চেনেন এমন লোকেদের সাথে যোগাযোগ করে (যোগাযোগের কোন মাধ্যম ব্যবহার করে)?	১	২	৩	৪	৫	৬	৭	৮	৯
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তারা যেভাবে তাদের সাথে যোগাযোগ করে যাদের তারা ভালভাবে জানে না (যোগাযোগের কোন মাধ্যম ব্যবহার করে)?	১	২	৩	৪	৫	৬	৭	৮	৯
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যেভাবে অন্য মানুষ তাদের সাথে যোগাযোগ করে?	১	২	৩	৪	৫	৬	৭	৮	৯
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স্বাস্থ্য:

তাদের শারীরিক স্বাস্থ্য?	১	২	৩	৪	৫	৬	৭	৮	৯
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তাদের যেভাবে ঘুরাফেরা করে?	১	২	৩	৪	৫	৬	৭	৮	৯
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তারা কিভাবে ঘুমাবে?	১	২	৩	৪	৫	৬	৭	৮	৯
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তাদের দেখার উপায়?	১	২	৩	৪	৫	৬	৭	৮	৯
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তাদের সহকর্মীদের সাথে একাডেমিকভাবে রাখার ক্ষমতা?	১	২	৩	৪	৫	৬	৭	৮	৯
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তাদের সমবয়সীদের সাথে শারীরিকভাবে রাখার ক্ষমতা?	১	২	৩	৪	৫	৬	৭	৮	৯
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বিশেষ সরঞ্জাম

প্রশ্ন: আপনার সন্তানের অনুভূতি কেমন মনে হয়...

খুবই অসুখী	অসুখী	সুখী বা অসুখী না	সুখী	খুব সুখী
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তাদের বাড়িতে যে বিশেষ সরঞ্জাম রয়েছে (যেমন বিশেষ বসার জায়গা, দাঁড়ানো ফ্রেম, হুইলচেয়ার, ওয়াকার)? অথবা <input type="checkbox"/> আমার সন্তানের বাড়িতে কোনো বিশেষ সরঞ্জাম নেই	১	২	৩	৪	৫	৬	৭	৮	৯
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তাদের স্কুলে কি বিশেষ সরঞ্জাম আছে? (যেমন বিশেষ আসন, দাঁড়ানো ফ্রেম, হুইলচেয়ার, ওয়াকার)? অথবা <input type="checkbox"/> আমার সন্তানের কোন বিশেষ সরঞ্জাম নেই স্কুলে	১	২	৩	৪	৫	৬	৭	৮	৯
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বিশেষ সরঞ্জাম যা পাওয়া যায় সম্প্রদায় এ (র্যাম্প, এসকেলেটর, হুইলচেয়ার অ্যাক্সেস)? অথবা <input type="checkbox"/> আমার সন্তানের কোন বিশেষ সরঞ্জামের প্রয়োজন নেই সম্প্রদায় এ	১	২	৩	৪	৫	৬	৭	৮	৯
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ব্যথা এবং বিরক্ত

পরবর্তী কয়েকটি প্রশ্ন আপনার সন্তানকে বিরক্ত করতে পারে এমন জিনিসগুলি সম্পর্কে জিজ্ঞাসা করে।

মোট বিরক্ত না

খুব বিরক্ত

আপনার সন্তান কি হাসপাতালে পরিদর্শন দ্বারা বিরক্ত?	১	২	৩	৪	৫	৬	৭	৮	৯
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স্বাস্থ্যগত কারণে স্কুল মিস করলে আপনার সন্তান কি বিরক্ত হয়?	১	২	৩	৪	৫	৬	৭	৮	৯
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আপনার সন্তান কি অন্য লোকদের দ্বারা পরিচালিত হয়ে বিরক্ত হয়?	১	২	৩	৪	৫	৬	৭	৮	৯
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কখনই না	খুব কমই	কখনও কখনও	প্রায়ই	সর্বদা
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ভবিষ্যতে কে যত্ন নেবে তা নিয়ে কি আপনার সন্তান চিন্তিত?	১	২	৩	৪	৫	৬	৭	৮	৯
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বাংলাদেশ হেল্থ প্রফেশন্স ইনস্টিটিউট (বিএইচপিআই)
Bangladesh Health Professions Institute (BHPI)
(The Academic Institute of CRP)

Ref:

CRP/BHPI/IRB/03/2023/709

Date:

13/03/2023

To
Syeda Nasrin Begum
B.Sc. in Physiotherapy
Session: 2017-2018, DU Reg. No: 8649
BHPI, CRP, Savar, Dhaka- 1343, Bangladesh

Subject: Approval of the dissertation proposal “Sleep Disturbance and Quality of Life among Children with Cerebral Palsy” by ethics committee.

Dear
Syeda Nasrin Begum,
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 and professor Md. Obaidul Haque, Vice-Principal, BHPI, as dissertation supervisor. The following documents have been reviewed and approved:

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

The purpose of the study is to find out the sleep disturbance and quality of life among children with cerebral palsy. Should there any interpretation, type, spelling, grammatical mistakes in the title, it is the responsibilities of the investigator. Since the study involves a questionnaire that takes a maximum of 20-30 minutes and have no likelihood of any harm to the participants, the members of the Ethics committee approved the study to be conducted in the presented form at the meeting held at 09:00 AM on January 9, 2023, at BHPI, 34th 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 in accordance with the Nuremberg Code 1947, the World Medical Association Declaration of Helsinki, 1964 - 2013, and other applicable regulations.

Best regards,

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

Date: 30 March, 2023

To

Head

Department of Physiotherapy

Centre for the Rehabilitation of the Paralysed (CRP)

Through: Head, Department of Physiotherapy, BHPI

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

Sir,

With due respect and humble submission to state that I am Syeda Nasrin Begum, a student of 4th year B. Sc. in Physiotherapy at Bangladesh Health Professions Institute (BHPI). The Ethical Committee has approved my research project entitled: **"Sleep disturbance and quality of life among children with cerebral palsy."** under the supervision of Professor Md. Obaidul Haque, Vice Principal, Bangladesh Health Professions Institute (BHPI), CRP, Savar, Dhaka-1343. Conducting this research project is a partial fulfilment of the requirement for the degree of B.Sc. in Physiotherapy. I want to collect data for my research project from the Department of Physiotherapy at CRP. So, I need your kind permission for data collection at Paediatric Unit of CRP at Savar, Dhaka. I would like to assure that anything of the study will not be harmful for the participants.

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

Sincerely

Syeda Nasrin Begum

Syeda Nasrin Begum

4th year B.Sc. in Physiotherapy

Class Roll: 28

Session: 2017-18

Bangladesh Health Professions Institute (BHPI)

An academic institution of CRP

Chapain, CRP, Savar, Dhaka-1343

Recommended & Forwarded
30.03.23
Prof. Md. Obaidul Haque
Vice-Principal
BHPI, CRP, Savar, Dhaka

Approved
30.03.23
Dr. Mohammad Anwar Hossain, PhD
Senior Consultant & Head
Physiotherapy Department
Associate Professor, BHPI
CRP, Savar, Dhaka-1343

Recommended from dept.
Shafiq
30.03.23
Md. Shafiqul Islam
Associate Professor & Head
Department of Physiotherapy
Bangladesh Health Professions Institute (BHPI)
CRP, Chapain, Savar, Dhaka-1343