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RELATIONSHIP BETWEEN SLEEP PROBLEMS AND GROSS MOTOR FUNCTION IN CHILDREN WITH CEREBRAL PALSY AND INVESTIGATION OF THEIR PARENTS' QUALITY OF LIFE

ORIGINAL ARTICLE

ABSTRACT

Purpose: Sleep problems commonly seen in children with cerebral palsy (CP) adversely affect daily living activities and treatment participation. The study aimed to investigate the relationship between sleep problems and gross motor function levels in children with spastic CP and to determine parents' quality of life (QOL).

Methods: Sixty children with spastic CP and 60 typically developing children between the ages of 4 and 12 years and their parents were enrolled in the study. After obtaining demographic data, Gross Motor Function Classification System (GMFCS) was used to determine motor function levels. International Classification of Diseases-10 was used for cognitive function. Children's Sleeping Habits Questionnaire measured children's sleeping habits. The Nottingham Health Profile was used to evaluate parents' QOL.

Results: Fifty-two (86.7%) children with CP had sleep disorders. Sleep disturbance values were significantly higher in the CP group than the controls (52.7±7.6 vs 41.5±8.01, respectively), p=0.001. There was no significant difference between GMFCS levels and sleep disorders in children with CP (p>0.05) except morning fatigue (p=0.028). There was no difference between cognition, medication use, and sleep problems (p>0.05). Parents' QOL was found to be worse in the CP group (p=0.001).

Conclusion: Rate of sleep disorders in children with CP was higher than controls. Their mothers' QOL values were found to be worse. Conditions that may be associated with sleep disorders in children with CP and their parents' conditions need to be better identified and screened.

Key Words: Cerebral Palsy; Gross Motor Function; Parents, Quality of Life; Sleep Disorders.

SEREBRAL PALSİLİ ÇOCUKLARIN UYKU PROBLEMLERİ VE KABA MOTOR FONKSİYON İLİŞKİSİ VE EBEVEYNLERİNİN YAŞAM KALİTESİNİN İNCELENMESİ

ARAŞTIRMA MAKALESİ

Ö7

Amaç: Serebral palsili (SP) çocuklarda yaygın olan uyku problemleri, günlük yaşam aktivitelerini ve tedaviye katılımı olumsuz etkilemektedir. Çalışmanın amacı, spastik SP'li çocuklarda uyku problemleriyle kaba motor fonksiyon seviyeleri arasındaki ilişkiyi ve ebeveynlerin yaşam kalitelerini arastırmak olarak belirlendi.

Yöntem: Çalışmaya, 4-12 yaş aralığında 60 spastik SP'li ve 60 tipik gelişen çocuk, ebeveynleri ile birlikte dahil edildi. Demografik verilerin alınmasının ardından motor fonksiyon seviyelerini belirlemek için Kaba Motor Fonksiyon Sınıflama Sistemi (KMFSS) kullanıldı. Çocukların uyku alışkanlıkları Çocuk Uyku Alışkanlıkları Anketi ile ölçüldü. Kognitif fonksiyonlar için Uluslararası Hastalıklar Sınıflaması-10 kullanıldı. Ebeveynlerin yaşam kalitesi algıları Nottingham Sağlık Profili ile değerlendirildi.

Sonuçlar: Elli iki (% 86,7) SP'li çocukta uyku bozuklukları tespit edildi. SP'li grubun uyku bozukluğu değerleri kontrol grubuna göre anlamlı şekilde yüksek bulundu (52,7±7,6 ve 41,5±8,01), p=0,001. SP'li çocukların KMFSS seviyeleri ve uyku bozuklukları arasında sabah yorgunluğu dışında (p=0.028) anlamlı farklılık yoktu (p>0.05). Kognitif durum, ilaç kullanımı ve uyku bozuklukları arasında fark yoktu (p>0.05). SP grubundaki ebeveynlerin yaşam kalitesi algılarının daha kötü olduğu bulundu (p=0,001).

Tartışma: Çalışmamız SP'li çocukların uyku bozukluğu oranının kontrol grubundan daha yüksek olduğunu gösterdi. Bu çocukların ebeveynlerinin yaşam kalitesi değerlerinin daha kötü olduğu bulundu. SP'li çocuklarda uyku bozuklukları ile ilişkili olabilecek durumların ve ebeveynlerin durumlarının daha iyi tanımlanmasına ve taranmasına ihtiyaç vardır.

Anahtar Kelimeler: Serebral Palsi; Kaba Motor Fonksiyon; Ebeveyn; Yaşam Kalitesi; Uyku Bozuklukları.

INTRODUCTION

Children with cerebral palsy (CP) have a higher prevalence of sleep disorders when compared to children without chronic health conditions (1). It is estimated that 13-85% of such children are afflicted with clinically significant sleep disorders (2). Sleep may be affected by many factors that are common in CP. Muscle spasms, other forms of musculoskeletal pain and the decreased ability to change body position during the night may all contribute to sleep difficulties and are related to the primary motor impairment (1).

Earlier studies have shown that over 35% of cases applying to a neuropsychiatric center for their sleep problems are children with developmental disorders, epilepsy, brain damage, or similar neurologic impairments. Among children with mental developmental failure and brain damage, certain deviances in the normal sleep cycle are measured to detect sleep problems due to the irregular secretion of hormones arising from the altered perception of light (3).

In children with CP, there is a higher prevalence of initiation and maintenance of sleep, sleep-wake transition disorders, and excessive sleepiness during the day and arousal (1). Children with CP are likely to have apnea or hypopnea during each hour of sleep due to the aspiration triggered by the limited change in body position, hypersalivation, macroglossia, and gastroesophageal reflux (2,3). Such sleep disorders adversely affect daily activities and school performance of children with CP in the development age. Due to the changes in the muscle tone of children with CP, several problems occur in respiratory muscles resulting in abnormal upper airway control, which then induce sleep disorders (4,5). Failure in having a good night sleep adversely impacts the life quality of the child and significant behavioral problems may impede the rehabilitation process as well (5,6).

Gross motor function level in children with CP is an important determinant of quality of life (QOL) (7). The effects of gross motor function limitation, activity limitations (8), mobility, and functional independence (9) are also seen in children with CP. On the other hand, typically developing children and adolescents have also been reported to have

sleep problems. According to the literature, these problems are sleepwalking, nightmares, talking during sleep, snoring, obstructive sleep apnea (OSA), unconscious waking, wetting, delayed sleep phase disorder (10), difficulty in falling asleep, difficulty in waking up in the morning, and frequent and unreasonable waking at night (11).

Based on the literature, the presence of sleep disorders even in children with typical development raised the question of which extent sleep disorders would occur in children with physical disabilities. The second question of the study was about children's parents. The altered pattern of sleep in individuals with CP directly affects parents' physical and emotional well-being (12). The disruption of standard sleep patterns may have an enormous impact upon the interactive and cognitive skills of the children with CP, adversely affect their QOL and interfere with the standard sleeping patterns of siblings and parents (13). Since mothers are the primary caregivers of the child, we aimed to investigate whether their perception of the QOL was affected by their kids' sleep problems.

METHODS

This cross-sectional study was conducted between January 2013 and August 2014. Upon receiving the approval from the Ethics Committee of Bolu Abant Izzet Baysal University (Approval Date: 20.12.2012 and Approval Number: 2012/244), patients' files of 150 children with CP aged 4-12 years under the rehabilitation service in a special education and rehabilitation center in the city of Düzce, Turkey, were accessed. Among these children, parents of 70 spastic children with CP matched our criteria were interviewed. The children with spastic CP were included in the study because of the higher number of children in this type generally in the specialized education centers. Inclusion criteria were being an age range between 4 and 12 years, diagnosed with spastic CP by a pediatric neurologist based on international CP criteria (14), and undergoing rehabilitation in a special education and rehabilitation center. Children whose mothers could not be reached (n=6) and who did not belong to the identified age range (n=4) were excluded from the study.

The CP group consisted of parents and their children with spastic CP (n=60) who provided a signed informed consent form to participate in the study. Sixty age-matched children with typical development, and their parents were served as the control group. Children in the control group consisted of close relatives of those in the CP group. The children in the control group were not siblings of the CP group, so the mothers were not the same. Inclusion criteria for controls were aged between 4 and 12 years, having no orthopedic, chronic, respiratory, psychiatric or neurologic disease, and being volunteered for the participation in the study. Written informed consents were collected from all parent participants and children who could sign. The mothers who were the primary caregivers fulfilled all items in the questionnaires.

Within the scope of this study, the demographic features of children were collected. The presence of the use of medications was recorded. Gross motor function levels were examined within the context of the Gross Motor Function Classification System (GMFCS). The GMFCS is a classification system developed for children with CP by Palisino et al. The level I means the least effect on motor function for a child with CP, while level V refers to severe involvement. Level I is the most independent level in motor function, while level V is the least independent (15). Turkish validity was performed by El et al. (16).

Cognitive function of children was measured using a form completed by the parents. The original form was accessed from SPARCLE (The Study of Participation of Children with Cerebral Palsy Living in Europe) Project. Cognitive function of children was measured using ICD-10 (International Classification of Diseases-10). According to this evaluation, learning disability is defined as mild in children with a cognitive function 50 to 70 and severe if it is less than 50 (17).

In this study, children's sleep habits were evaluated via the Children's Sleep Habits Questionnaire (CSHQ) completed by their parents. The CSHQ, created by Owens et al., is a screening instrument for children based on clinical symptom presentations of common sleep disorders, and is a 45-item parental questionnaire (18). This questionnaire basically

queries four sleep parameters, but there are several subscales of these parameters. The main domains are bedtime, sleep behavior, waking during the night, and morning wake-up. Sub-parameters of sleep disorders consist of items such as difficulty in falling into sleep, snoring, nightly wake-ups, OSA, asking for the parent when waking up at night, morning fatigue, and resistance to sleep and feeling discomfort during sleep. Test-retest reliability of the test was acceptable (range 0.62-0.79). The result of the test is given as a total score. A cut-off total CSHQ score of 41 identifies children with a clinical sleep problem with a sensitivity of 0.80 and specificity of 0.72. It is a three-point scale which is expected to be marked the most appropriate one as "usually, sometimes and rarely" (18). In our study, the mean sleep scores of the children were given for both groups. In addition, children who scored 41 and above from the questionnaire were presented as a percentage of all participants in both groups. Fiş et al. performed Turkish validity study of the questionnaire. It is a valid and reliable tool for screening and evaluating sleep problems and habits in Turkish children (19).

The QOL of parents was analyzed using the Nottingham Health Profile (NHP). The NHP is a 38-item yes/no questionnaire consisting of six subscales: physical mobility, social isolation, sleep, pain, emotional reactions, and energy (20). This survey was preferred because it reliably examines the general anxiety, stress expression, and life status in the general adult population. In this questionnaire, the higher score identifies the worse QOL (21).

All of the evaluation parameters were applied to the children in the control group, excluding GMFCS and cognition. Control group's parents' data were obtained with NHP as well. All permissions were obtained for the evaluation tools, and Turkish versions of the tools were used in the study.

Statistical Analyses

According to the reference study (22), the CSHQ results had a large effect size (d=0.757). Assuming we could achieve a lower effect size level (d=0.500), a power analysis was performed before the study. Accordingly, inclusion of at least 102 participants (51 CP children and 51 controls) would result in 80%

Table 1: Characteristics of the Participants.

Variables	CP Group (n=60)	Control Group (n=60)	р	
	Mean±SD	Mean±SD		
Age (years)	8.30±3.15	7.95±2.76	0.953	
Height (cm)	119.43± 24.25	131.13±16.84	0.004*	
Weight (kg)	24.56±1.28	30.13±1.10	0.001*	
Gender (Male/Female)	29/31	29/31	1.000	

^{*}p<0.05.

power with 95% confidence interval. All statistical analyses were performed using SPSS 24.0 (IBM SPSS Statistics 24 software, IBM Corp, Armonk, NY, USA). While the measured scores of cases were expressed is mean and standard deviations, age groups and extremity distributions were expressed as frequencies and percentages (%). The difference of groups was assessed using Chisquare test (the difference between sleep problems and GMFCS levels was analyzed using Chi-square test). Mann-Whitney U test was used to determine the difference in parents' QOL. In addition, the relationships between continuous variables were analyzed using Spearman's correlation analysis. Statistical significance level was accepted as p<0.05.

RESULTS

The study was conducted a total of 60 spastic CP cases within a mean age of 8.30±3.15 years. Twenty-nine (48.3%) of them were females, while 31 (51.7%) were males. Sixty sex-matched children with typical development with a mean age of 7.95±2.76 years were included in the study as controls. The demographic and clinical

characteristics of the subjects are presented in Table 1. There was no significant difference in age and gender between the CP and control groups (p>0.05).

The majority of cases exhibited clinically severe degrees of motor function. Based on extremity distributions 13 children (21.7%) were hemiparetic (n=9 for GMFCS level I, n=1 for GMFCS level II, n=1 for GMFCS level III, and n=2 for GMFCS level V), 19 children (31.7%) were diplegic (n=2 for GMFCS level II, n=6 for GMFCS level II, n=7 for GMFCS level III, n=3 GMFCS for level IV, and n=1 GMFCS for level V), and 28 children (46.6%) were quadriplegic (n=1 for GMFCS level III, n=5 for GMFCS level IV, and n=22 for GMFCS level V). There were 11 children (18.3%) at GMFCS level I, seven children (11.7%) at GMFCS level III, nine children (15%) at GMFCS level III, eight children (13.3%) at GMFCS level IV, and 25 children (41.7%) at GMFCS level V.

In this study, CSHQ total score of the CP group was found as 52.7 ± 7.6 . Abnormal CSHQ total sleep score was obtained in 86.7% (n=52) of the children in the CP group.

Among those 52 children with sleep problems, the

Table 2: Sleep Scores and the Distribution of Sleep Problems Based on Gross Motor Function Classification System Levels.

Variables	CP Group		Control Group			_	
	Mean±SD	Median	min-max	Mean±SD	Median	min-max	P
CSHQ Total Score	52.70±7.60	53	34-68	41.50±8.01	39.5	33-58	<0.001*
	GMFCS						
	GMFCS Level I	GMFC Level	-	GMFCS Level III	GMFCS Level IV		<0.001*
With Sleep Problems (n, %)	10 (90.9)	6 (85.7	')	8 (88.9)	8 (100)	20 (80)	0.497
Having Morning Fatigue (n, %)	4 (36.4)	6 (85.7	') 4	4 (44.4)	5 (62.5)	6 (24)	0.028*

^{*}p<0.05, GMFCS: Gross Motor Function Classification System, CSHQ: Children's Sleep Habits Questionnaire.

Table 3: Comparison of Parents' Quality of life in Both Groups.

Variables	CP Group		Control Group		
	Median	min-max (n=60)	Median	min-max (n=60)	р
NHP Total Score	119.54	0-499.72	52.37	0-462.90	<0.001*
Pain	8.96	0-100	7.39	0-100	0.155
Emotional Reactions	22.48	0-100	0.00	0-100	<0.001*
Social Isolation	22.01	0-100	0.00	0-55.46	<0.001*
Physical Mobility	0.00	0-41.86	11.37	0-43.90	0.001*
Energy Level	36.80	0-100	0.00	0-100	0.028*
Sleep	12.57	0-77.63	6.28	0-77.63	0.417

^{*}p<0.05. CP: Cerebral Palsy, NHP: Nottingham Health Profile.

most common sleep disorder was asking for the parent at night with a rate of 73.3% and waking up at night with a rate of 60%, falling asleep disorder with a rate of 50%, restlessness in sleep with a rate of 56.7%, and morning fatigue with a rate of 41.7%. Control group's total CSHQ score was 41.5±8.01. We found that 21 of 60 children with typical development (35%) had sleep problems. The rates of sleep disorders in typically developing children were as follows: waking up at night was 21.7%, asking for parent was 20%, and resistance to sleep was 20%.

In the comparison of sleep problems, the CP group showed worse total scores than the controls (p<0.001) (Table 2). Upon analyzing the subparameters, there was a significant difference in morning fatigue parameter and motor function level of the CP group (p=0.028) (Table 2). The majority of children at GMFCS level II and V were experiencing morning fatigue.

No significant difference was found between the GMFCS level of children and sleep disorders score (p>0.05) (Table 2). This result was approved with Spearman's correlation analysis as well (r=-0.092, p=0.487).

In the CP group, 18 children had a normal cognitive function (Intelligence Quotient, IQ>70). Fifteen of them experienced sleep problems (28.8%). Fourteen children had mild cognitive impairment (50<IQ<70) and 11 of them (21.2%) had sleep problems. In addition, 28 children had severe cognitive impairment (IQ<50), and 26 of them (50%) had sleep problems. Twenty-two children with CP were taking medications. The 31.6% of

children with sleep problems (n=19) were the ones who were taking medications. We did not find any significant differences in medication use, cognitive function, and sleep problems (p>0.05).

According to the NHP data, the median score of parents' perceived QOL in the CP group was 119.54. The most affected sub-parameters were emotional reactions, social isolation, physical mobility, and energy. Parents in the control group showed better scores in NHP than the parents in the CP group (p=0.001) (Table 3). There was no statistically significant difference between NHP scores of mothers of CP group with or without sleep problems (CP with sleep problems median score was 114.82, and CP without sleep problems median score was 207.15, p=0.355).

DISCUSSION

This is the first study investigating the level of the GMFCS, sleep problems, and QOL of their parents in Turkish children with CP. In this study, the majority of children in CP group were in GMFCS level V. Sleep problems were found 86.6% of children with spastic CP. Although there was no difference between the GMFCS scores of the children, sleep problems total scores, and morning fatigue were the primary affected sleep disorder because the majority of children at GMFCS level II and level V were experiencing morning fatigue. There was no difference between cognition, medication use, and sleep problems. Comparing the control group, children with CP showed much more sleep problems based on the CSHQ scores. Parents who had children with CP had worse scores in NHP.

In the study conducted by Romeo et al. (23) abnormal

sleeping scores was found 13% of children with CP, and there was at least one abnormal score in sleep questionnaire in %35. Another study of Romeo et al. (24) found that more than 40% of children with CP presented with at least one sleep disorder, and there was a relationship between sleep disturbance and GMFCS level V. McCabe et al. (25) argued that several sleep problems exist in each GMFCS level. The children and adolescents with CP were reported to be affected by sleep disorders at any age and every GMFCS level (25). Hemmingsson et al. (6) claimed that sleep problems are even more severe among children in GMFCS level IV and V. Adiga et al. (26) reported that there was no significant correlation between GMFCS levels and sleep disorders. In this study, we found sleep disorders in each GMFCS levels. There is a discrepancy in the literature, regarding GMFCS levels and sleep problems. Some sources argue that those two parameters are related, and some state the opposite. According to the literature, it is not possible to say that sleep disorders are correlated with increased GMECS levels.

In our study, the only significant difference between GMFCS levels and sleep problems was found in morning fatigue. However, we thought that this was due to the accumulation of the amount of children in level II and V having morning fatigue.

In their study Elsayed et al. included 100 children with CP, aged between 2 and 12 years, and found a high incidence of sleep problems in both preschool and school-age groups. Pre-school children have more prevalence for early insomnia (46.2%), while school group suffers more sleep-disordered breathing (50%), more nightmares (50%), more sleep talking (12.5%), and more excessive daytime sleepiness (62.5%) (27). Another study reported that 43.8% of children with CP, between 6 and 12 years, had sleep problems (1). The most common sleep disorder in both preschool- and school-age children with CP was problem in the initiation and maintenance of sleep (1). The 44% of children with CP had clinically significant symptoms in one or more sleep disorder, notably, 59.5% were schoolaged children (28). These results and our findings show similarities based on sleep disorders seen in children with CP, However, in this study, we could not make a grouping as preschool children because

the minimum age was four years old. This could be one of this study's limitations.

In another study, researchers reported that snoring (9.6%), insomnia (12.8%), and sleep-related breathing disorders (18.1%) were the most common problems in children with CP (4). In this study, sleep disorders of children varied such as snoring (33%), difficulty in falling into sleep at night (50%), nightly wakeups (60%), asking for parent while falling into sleep (73.3%), OSA (21.6%), resistance to sleep (41.6%), restlessness in sleep (56.6%), and morning fatigue (41.6%). In this study, the prevalence of sleep problems was 86.6% among 60 children with spastic CP and 35% among 60 typically developing children. Having a physical disorder may affect child's sleep pattern. The relatively higher rates compared to the literature could be attributed to cultural differences between Turkey and the other countries. Sleep advice given to children by their families in Turkey, sleep habits, and various factors affecting sleep should be examined in future studies.

Besides questioning the sleep, we investigated the cognitive function and medication use in children with CP. We could not find any difference between cognition, medication use, and sleep problems. However, we did not ask the parents the kind of medication taking by their children, any possible side effects, dose, and the time of the day of the medication. Since medication could affect child's sleep pattern, the medication use should be investigated in further study in detail. This was another limitation of this study.

Wayte et al. (22) stated that children's sleep disorders were significantly correlated with their mothers' sleep disorders. Mothers of children with CP have a high rate of sleep problems, and their QOL is highly associated with maternal depression. In this study, we investigated parents' perceived QOL using the NHP. Since taking care of a disabled child all day long is comparable to a full-time job, it must be tiring both physically and mentally. We used this tool since it is easy to apply and easily understood by the participants. Based on the data, the most affected sub-parameters of perceived QOL were found as emotional reactions, social isolation, physical mobility, and energy. Parents in

the control group showed better NHP scores. The fact that families with disabled children having sleep problems negatively affected their perception of QOL. Further study may assess QOL using more specific questionnaires.

In conclusion, we pointed out that sleep disturbances are critical problems in children with CP, and should be investigated with more comprehensive evaluation tools. Parents and especially mothers, as they are the primary caregivers, undertake a demanding full-time task, no matter how willing they are. Further study is need to investigate the factors related to sleep problems.

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Conflict of Interest: Authors declare no conflict of interest.

Ethical Approval: The study protocol was approved by Bolu Abant İzzet Baysal University Ethics Committee (Approval Date: 20.12.2012 and Approval Number: 2012/244).

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Author Contributions: Concept – ŞA; Design – ŞA; Supervision - ŞA; Resources and Financial Support – DK; Materials - DK; Data Collection and/or Processing – DK; Analysis and/or Interpretation – ŞA, DK; Literature Research - DK; Writing Manuscript – DK, ŞA; Critical Review – ŞA.

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