Hüsrevoğlu S., Özdemir Görgü S., Tarakçı D., Evaluation of Family Impact of Children with Cerebral Palsy and Family Caregiver's Quality of Life, Sleep Quality and Individual Physical Education Satisfaction: A Mixed Study, Turk J Physiother Rehabil. 2024; 35(3):342-351. doi: 10.21653/tjpr.1410489

EVALUATION OF FAMILY IMPACT OF CHILDREN WITH CEREBRAL PALSY AND FAMILY CAREGIVER'S QUALITY OF LIFE, SLEEP QUALITY AND INDIVIDUAL PHYSICAL EDUCATION SATISFACTION: A MIXED STUDY

ISSN: 2651-4451 • e-ISSN: 2651-446X

Turkish Journal of Physiotherapy and Rehabilitation

2024 35(3)342-351

Sare HÜSREVOĞLU, PT, MSc[1]
Sena ÖZDEMİR GÖRGÜ, PT, PhD[2]
Devrim TARAKÇI, PT, PhD[1]

ORIGINAL ARTICLE

ABSTRACT

Purpose: Cerebral Palsy (CP) is a disease that has significant effects on both the child and the family. The objective of this study is to examine the influence of the family, quality of life, sleep quality and individual physical education (IPE) of family caregivers of children with CP. In addition, it is planned to detail the factors affecting their satisfaction through semi-structured individual interviews.

Methods: Family caregivers of 55 children diagnosed with CP between the ages of 1 and 15 were included in the study. Demographic information with "Demographic Information Survey", the functional status of the child's with "Gross Motor Function Classification System (GMFCS)" the impact of the child on the family with "Impact on Family Scale (IoFS)", caregiver's quality of life with "World Health Organization Quality of Life Scale - Short Form (WHOQOL-BREF) ", caregiver's sleep quality was evaluated with " Pittsburgh Sleep Quality Index (PSQI)" and the satisfaction with IPE was questioned with the "Pediatric Quality of Life Healthcare Parental Satisfaction Scale (PedsQL)". Qualitative data were obtained through semi-structured individual interviews.

Results: In our study, GMFCS level was negatively correlated with WHOQOL-BREF (p=0.028) and positively correlated with PSQI (p=0.002). In addition, the IoFS scale correlated negatively (p=0.000) with WHOQoL-BREF and positively (p=0.016) with PSQI.

Conclusion: The findings of this study indicate that the physical dependence of the child has a negative impact on the quality of life and sleep quality of caregivers, and that the number of siblings affects their satisfaction with the treatment. It is recommended that further information be obtained regarding caregivers' perceptions of the disease and their individual physical education needs, as a result of semi-structured individual interviews.

Keywords: Cerebral palsy, family, personal satisfaction, physical education, quality of life

SEREBRAL PALSİLİ ÇOCUKLARIN AİLE ETKİLENİMİ VE AİLEDEKİ BAKIM VERENİN YAŞAM KALİTESİ, UYKU KALİTESİ VE BİREYSEL BEDEN EĞİTİM MEMNUNİYETİNİN DEĞERLENDİRİLMESİ: KARMA ÇALIŞMA

ARAŞTIRMA MAKALESİ

ÖZ

Amaç: Serebral Palsi (SP), hem çocuk hem de aile üzerinde önemli etkileri olan bir hastalıktır. Bu çalışmanın amacı, SP'li çocukların aile etkilenimini ve ailedeki bakım verenin yaşam kalitesini, uyku kalitesini ve bireysel beden eğitiminden (IPE) memnuniyetini incelemektir. Ayrıca yarı yapılandırılmış bireysel görüşmelerle de memnuniyetini etkileyen faktörlerin detaylandırılması planlanmıştır.

Yöntem: Çalışmaya 1-15 yaş aralığında SP tanısı almış 55 çocuğun bakım vereni dahil edilmiştir. Demografik bilgiler "Demografik Bilgiler Anketi" ile, çocuğun fonsiyonel durumu "Kaba Motor Fonksiyon Sınıflandırma Sistemi (KMFSS)" ile, çocuğun aile üzerindeki etkisi "Aile Etki Ölçeği (AEÖ)" ile, bakım verenin yaşam kalitesi "Dünya Sağlık Örgütü Yaşam Kalite Ölçeği – Kısa Form (DSÖYKÖ-KF)" ile, bakım verenin uyku kalitesi "Pittsburgh Uyku Kalitesi İndeksi (PUKİ)" ile ve bakım verenin çocuğunun aldığı bireysel bedensel eğitimden memnuniyeti "Pediatrik Yaşam Kalitesi Sağlık Bakımı Ebeveyn Memnuniyet Ölçeği (PYKSBEMÖ)" ile değerlendirilmiştir. Nitel veriler ise, yarı yapılandırılmış bireysel görüşmeler ile sağlanmıştır.

Sonuçlar: Çalışmamızda KMFSS seviyesinin DSÖYKÖ-KF ile negatif (p=0,028), PUKİ ile pozitif (p=0,002) korelasyon gösterdiği bulunmuştur. Ayrıca AEÖ ölçeği DSÖYKÖ-KF ile negatif (p=0,000), PUKİ ile pozitif (p=0,016) korelasyon göstermektedir.

Tartışma: Bu çalışmanın bulguları, çocuğun fiziksel bağımlılığının bakım verenlerin yaşam kalitesi ve uyku kalitesi üzerinde olumsuz bir etkiye sahip olduğunu ve kardeş sayısının tedaviden memnuniyetlerini etkilediğini göstermektedir. Yarı yapılandırılmış bireysel görüşmeler sonucunda bakım verenlerin hastalık algıları ve bireysel beden eğitimi ihtiyaçları hakkında daha fazla bilgi edinilmesi önerilmektedir.

Anahtar kelimeler: Serebral palsi, aile, kişisel memnuniyet, bedensel eğitim, yaşam kalitesi

1 Istanbul Medipol University, Department of Physiotherapy and Rehabilitation, Faculty of Health Science, Istanbul, Turkey
2 Istanbul Medipol University, Department of Orthosis and Prosthetics, Faculty of Health Science, Istanbul, Turkey

Correspondence (İletişim):

Sare HÜSREVOĞLU
Istanbul Medipol University, Department of Physiotherapy and Rehabilitation, Faculty of Health Science, Istanbul, Turkey
E-mail: sarehusrevoglu@gmail.com
ORCID: 0000-0002-8985-2490

Sena ÖZDEMİR GÖRGÜ
E-mail: senaozdemir@medipol.edu.tr
ORCID: 0000-0002-5395-3185

Devrim TARAKÇI
E-mail: dtarakci@medipol.edu.tr
ORCID: 0000-0001-9804-368X

Received: 29.12.2023 (Geliş Tarihi)
Accepted: 01.09.2024 (Kabul Tarihi)

INTRODUCTION

Cerebral palsy (CP) is the most prevalent disease affecting motor function in newborns (1). The child's motor functions and body development are affected as a result of various injuries and malformations in the developing central nervous system (2). As reported by Serdaroğlu et al. (2006) in a study conducted in Turkey, the incidence of this condition was found to be 4.4 per 1,000 live births (3).

Given that CP emerges in early infancy and continues through to adulthood, it is essential to consider and manage the process within the context of development, functionality and family (1). Children with CP require varying degrees of assistance to enable them to continue with their daily lives. The provision of care and assistance to children with CP has a significant impact on family caregivers, both physically and psychologically (2,4). In addition, having more than one child can have a negative impact on these stresses. A number of studies have investigated the impact of a child with CP on the family. These studies have reported that the burden of caregiving can cause stress, depression, sleep problems, reductions in quality of life and loss of motivation in family caregivers (2,5–7).

The nature of the disease, may necessitate lifelong education and treatment for children with CP. In order to achieve this objective, it is common practice to utilise the services of special education and rehabilitation centres. In special education and rehabilitation centres, the Physically Disabled Support Training Program is implemented under the Ministry of National Education. Individual physical education (IPE) is provided to patients with physical disabilities. IPE programmes are designed in accordance with the individual support training programme established by the Ministry of National Education. A individualised education programme is devised and implemented for each child (8).

The degree of satisfaction with the health service is an important indicator in evaluating the quality of the service provided. The satisfaction of family caregivers with the health care provided to their children is a key indicator of the quality of the service provided (9,10). A multitude of studies involving patients with diverse pathologies have reported that the therapeutic relationship between patient and therapist has a beneficial impact on health satisfaction (10).

A review of the literature revealed a paucity of studies evaluating the educational outcomes of children with CP. Given the potential influence of various demographic characteristics, quality of life, quality of sleep and the effects of the child with CP on the family on satisfaction with education, a comprehensive study was deemed necessary. Furthermore, it was postulated that the level of GMFCS of the child with CP may also be a contributing factor to the caregiver's satisfaction with the IPE.

The objective of this study is to examine the influence of the family, quality of life, sleep quality and IPE of family caregivers of children with CP. In addition, it is planned to detail the factors affecting their satisfaction through semi-structured individual interviews.

METHODS

Study Design and Participants

This study is a prospective mixed study using experimental and in-depth individual interview method in order to evaluate the effects of family caregivers who have children with CP and to evaluate the IPE satisfaction they receive from the special education and rehabilitation center. Approval for the study was obtained at the meeting of Istanbul Medipol University Non-Interventional Clinical Research Ethics Committee dated 10/08/2022 (approval number E-10840098-772.02-4550) and the research was carried out in accordance with the Declaration of Helsinki.

Participants were selected from two different special education and rehabilitation centers in Turkey between August 2022 and May 2023. A multicentre trial was conducted in the same province in order to achieve the desired number of participants. The study included family caregivers of children aged between 1 and 15 years old who had been diagnosed with CP and who received regular intervention through the use of the IPE. The study sample was limited to caregivers with no more than one child with special needs, proficiency in Turkish, and no communication or cognitive difficulties. Evalu-

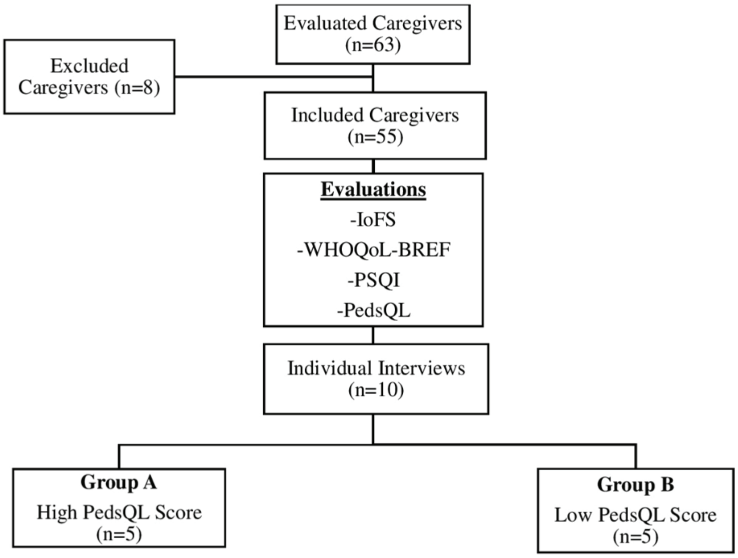

Figure 1. Flowchart of the Study

ations were made through questionnaires. A written consent form was furnished to respondents for review and signature before starting interviews. A total of 63 individuals participated in the study; however, due to the incomplete completion of eight questionnaires, the analyses were conducted on 55 participants. Flowchart is given in Figure 1.

Measures and Procedures

The demographic information of the family caregivers was questioned by the questionnaire prepared by the researcher. Each child's function level was recorded with the "Gross Motor Function Classification System (GMFCS)". The effect of the child with CP on the family was determined by the "Impact on Family Scale (IoFS)"; quality of life with "World Health Organization Quality of Life Scale – Short Form (WHOQOL-BREF)"; sleep quality with "Pittsburgh Sleep Quality Index (PSQI)"; satisfaction with IPE was questioned with the "Pediatric Quality of Life Health Care Parental Satisfaction Scale (PedsQL)". Qualitative data were obtained through semi-structured individual interviews.

Demographic Information Survey

A researcher-developed form was used to record demographic information about the family caregivers (degree of kinship, age, education level, occupation, marital status) and the child (number of siblings, gender, concomitant disease, age).

Gross Motor Function Classification System (GMFCS)

The GMFCS is a five-category motor classification tool that varies according to the age of the patient. The evaluation assesses the individual in a number of areas, such as mobility, posture and balance. As the level increases, functional independence decreases (11–13).

Impact on Family Scale (IoFS)

The questionnaire was originally developed by Stein and Riessman (14). The scale has a 4-point likert type evaluation and consists of a total of 33 items. In 2009, Bek et al. conducted a Turkish validity and reliability study. The study was deemed valid and reliable for children with special needs in Turkey, with the exception of the "Coping" subscale (15). A high score indicates family is highly affected by the situation (16).

World Health Organization Quality of Life Scale – Short Form (WHOQOL-BREF)

Developed by the World Health Organization (WHO), WHOQOL-BREF has 4 areas related to quality of life; physical health, psychological health, social relationships and environment (17). Turkish validity and reliability of the questionnaire was conducted by Eser et al. Turkey adaptation consists of 27 questions with the addition of 1 national question about the environment (18). Evaluation is graded on a 5-point likert scale, a high score indicates a high quality of life (17,19).

Pittsburgh Sleep Quality Index (PSQI)

PSQI assesses sleep quality in the past month and factors that may affect sleep quality in adults (20). In 1996, Ağargün et al. conducted Turkish validity and reliability studies on PSQI (21). Of the 24 questions in total, 19 questions are answered by self-report and 5 questions are answered by the spouse or roommate. Within the scope of this study, only self-report questions were answered. It is evaluated with a 4-point likert scale, a total score greater than 5 indicates poor sleep quality (20).

Pediatric Quality of Life Health Care Parental Satisfaction Scale (PedsQL)

Scale, developed by James W. Varni et al. (22). Turkish validity and reliability studies were carried out in 2016 by Ulus and Kublay (23). It consists of 6 subtitles and 25 questions, including information, family involvement, communication, technical skills, emotional needs and general satisfaction. Evaluated with a 5-point likert scale and higher score means more satisfaction (23,24).

Semi-Structured Individual Interviews

Semi-structured individual interviews were conducted with 10 of the family caregivers included in the study, based on the results of the PedsQL survey in which we assessed satisfaction with IPE. In order to prevent bias in the study, semi-structured interviews were conducted with individuals exhibiting varying degrees of satisfaction. The 10 people to be interviewed included the 5 people with the lowest PedsQL scores (Group A) and the 5 people with the highest PedsQL scores (Group B) (25,26). The objective of the interviews is to gain a comprehensive understanding of patients’ satisfaction with the treatment and to identify the underlying reasons. The questions posed in the interviews were constructed based on the clinical experiences of the researchers, expert opinions, and a comprehensive literature review. In order to ascertain the suitability of the draft questions, the opinion of an expert in the field was sought. The interviews were conducted online and recorded with the consent of the participants. Each interview lasted approximately 15 minutes.

Statistical Analysis

Power analysis was performed to determine the number of people to be included in the study. The power of the test was calculated with the G*Power 3.1 program. The data of our study were evaluated using the Statistical Package for Social Sciences (SPSS) 25.0 IBM Corp. Released 2017. IBM SPSS Statistics for Windows, Version 22.0 (SPSS INC., Chicago, IL, USA).

A comparable study in the relevant literature is that conducted by Lang et al. (2021), which calculated the effect size for the relationship between sleep quality and quality of life as 0.480. In order to exceed the 95% value in determining the power of the study, it is necessary to reach 42 people at a 5% significance level and an effect size of 0.480 (lower critical r = 0.257; upper critical r = 0.257). In the research, the objective was to reach 50 people in each group, given the high power of the test and the anticipated losses (20).

Frequency and percentage analyze were used to determine the descriptive characteristics of the participants, and mean and standard deviation statistics were used to analyze the scale. Kurtosis and Skewness values were examined to determine whether the research variables showed a normal distribution. Parametric methods were used in the analysis of the data.

The relationships between the dimensions determining the scale levels of the patients were examined through Pearson correlation analyses. Correlation coefficients (r) 0.000-0.250 very weak; 0.260-0.490 weak; 0.500-0.690 medium; 0.700-0.890 high; 0.900-1.000 is rated as very high. Independent groups t-test, one-way analysis of variance (Anova) and post hoc (Tukey, LSD) analyzes were used to examine the differences in the scale levels according to the descriptive characteristics of the patients (27).

In order to analyse the qualitative data, the recorded interviews were initially transcribed into written form. In the study, the researchers employed descriptive analysis, which is one of the qualitative analysis methods. In descriptive analysis, the objective is to elucidate and delineate a specific situation or occurrence in accordance with pre-established themes (28). Miles & Huberman (1994) reliability formula [Reliability = Consensus / (Agreement + Disagreement)] was used in the analysis of qualitative data, and the agreement between the researchers was determined as 88.75% (29). Miles and Huberman suggest that a qualitative study of sufficient quality should have a coding reliability of at least 80%. The results of the calculations show that the coding in this study is reliable.

RESULTS

The study included 55 family caregivers (4 Male/51 Female) who had CP (36 Boys/19 Girls) children and met the inclusion criteria. The majority of the family caregivers (89%) were mothers. The mean age of the caregivers was 39.380 ± 8.263 years, while the mean age of the children was 9.250 ± 4.660 years. The demographic information of the participants is provided in Table 1.

The distribution of GMFCS scores among the children of family caregivers who participated in the study is as follows: 23.6% are classified as level 1, 18.2% as level 2, 10.9% as level 3, 20.0% as level 4, and 27.3% as level 5. The results indicated that 56% of the participants exhibited poor sleep quality.

There was a statistically significant negative (p=0.028) correlation with the child's GMFCS level, the family caregiver's WHOQOL-BREF score, and a positive (p=0.002) correlation with the PSQI score. There was no statistically significant correlation between GMFCS level and IoFS and PedsQL scores (p>0.05).

There was no statistically significant relationship between the family caregivers's IoFS score and the education level (p=0.248), the total number of siblings of the child (p=0.582) and the concomitant disease of the child (p=0.899) (p>0.05).

There was no statistically significant relationship between the WHOQOL-BREF score of the caregivers and the educational level (p=0.693), the total number of siblings of the child (p=0.915) and the concomitant disease of the child (p=0.671) (p>0.05).

There was no statistically significant relationship between the caregiver's PSQI scores and the educational level (p=0.649), the total number of siblings of the child (p=0.960) and the concomitant disease of the child (p=0.406) (p>0.05).

Table 1. Distribution of Participants by Demographic Information

Groups	**n (%)**
Degree of Kinship	
Mother	49 (89.10%)
Grandmother	2 (3.60%)
Father	4 (7.30%)
Parent's Education Level	
Primary School	18 (32.70%)
Middle School	10 (18.20%)
High School	13 (23.60%)
University	14 (25.50%)
Parent's Occupation	
Housewife	46 (83.6%)
Nurse	1 (1.80%)
Accountant	1 (1.80%)
Teacher	3 (5.50%)
Technician	1 (1.80%)
Self-Employed	3 (5.50%)
Marital Status of the Parent	
Married	53 (96.40%)
Not Married	2 (3.60%)
Number of Siblings	
1	16 (29.10%)
2	22 (40.00%)
3 or more	17 (30.90%)
Gender	
Boys	36 (65.50%)
Girls	19 (34.50%)
Concomitant Disease	
No	33 (60.00%)
Yes	22 (40.00%)
	Mean±SD
Parent's Age (year)	39.38±8.26
Child's Age (year)	9.25±4.66

SD: Standard Deviation

There was no statistically significant relationship between PedsQL total and sub-parameter scores and the educational level of the caregiver and the child's concomitant disease (p>0.05). However, a difference was found between the total number of siblings of the child and the PedsQL total score of the family caregivers on the sub-parameters of

Table 2. Comparison of PedsQL Scores with Number of Siblings

	Group	n (%)	Mean±SD (N=55)	p
	1	16 (29.10%)	14.12±4.47	
Information	2	22 (40.00%)	15.59±5.01	0.172
	3	17 (30.90%)	12.05±7.42	
	1	16 (29.10%)	10.12±3.70	
Family Involvement	2	22 (40.00%)	13.40±3.55	**<0.05^{a,b}**
	3	17 (30.90%)	10.11±5.84	
	1	16 (29.10%)	12.68±4.72	
Communication	2	22 (40.00%)	16.09±5.29	0.132
	3	17 (30.90%)	13.11±6.81	
	1	16 (29.10%)	10.62±3.98	
Technical Skills	2	22 (40.00%)	13.50±3.62	**<0.05^{a,b}**
	3	17 (30.90%)	9.41±5.07	
	1	16 (29.10%)	11.50±4.06	
Emotional Needs	2	22 (40.00%)	13.60±3.55	**<0.05^{a,b}**
	3	17 (30.90%)	9.41±5.42	
	1	16 (29.10%)	7.62±3.09	
General Satisfaction	2	22 (40.00%)	9.91±2.50	**0.052**
	3	17 (30.90%)	7.50±4.54	
	1	16 (29.10%)	66.68±20.22	
Total	2	22 (40.00%)	82.13±18.95	**<0.05^{b}**
	3	17 (30.90%)	61.17±32.24	

PedsQL: Pediatric Quality of Life Healthcare Parental Satisfaction Scale, SD: Standard Deviation >: greater than, <: less than, ^{a}Significant change in favor group 2 compared with group 1, ^{b}Significant change in favor group 2 compared with group 3

family involvement, technical skills and emotional needs. The comparison of PedsQL scores with the number of siblings is given in Table 2.

The correlation analyzes between the evaluated scales are given in Table 3. When the analyzes were examined, statistically negative weak (p=0.028) between WHOQOL-BREF and GMFCS, negative moderate (p=0.000) between WHOQOL-BREF and IoFS, negative weak (p=0.011) between PSQI and WHOQOL-BREF, positive weak (p=0,002) correlation between PSQI and GMFCS, and a weak positive (p=0.016) correlation between PSQI and total IoFS. Correlation relationships between other variables were not statistically significant (p>0.05).

The responses to the individual interviews conducted using interview forms regarding the satisfaction of caregivers with the IPE received by children with CP were examined under four themes. These

Table 3. Correlation Analysis Between Scales

		GMFCS	IoFS	WHOQOL-BREF	PSQI	PedsQL
GMFCS	r	1.000				
	p	0.000				
IoFS	r	0.220	1.000			
	p	0.106	0.000			
WHOQOL-BREF	r	**-0.296***	**-0.512****	1.000		
	p	0.028	0.000	0.000		
PSQI	r	**0.412****	**0.322***	**-0.341***	1.000	
	p	0.002	0.016	0.011	0.000	
PedsQL	r	-0.132	-0.169	0.128	-0.054	1.000
	p	0.337	0.218	0.353	0.694	0.000

*<0,05; **<0,01; Pearson Correlation Analysis, GMFCS: Gross Motor Function Classification System, IoFS: Impact on Family Scale, WHOQOL-BREF: World Health Organization Quality of Life Scale – Short Form, PSQI: Pittsburgh Sleep Quality Index, PedsQL: Pediatric Quality of Life Healthcare Parental Satisfaction Scale

Table 4. Semi-Structured Individual Interview Results

THEMES	**Highest PesdQL Scores (n=5)**					**Lowest PedsQL Scores (n=5)**					
1. Opinions about disease diagnosis	A1	A2	A3	A4	A5	B1	B2	B3	B4	B5	Total (n=10)
I didn't want to accept the disease	x	x	x	x				x			5
As soon as I learned about the disease, I searched for a solution.					x	x	x		x	x	5
A1: *"I went to many different doctors. They were making the diagnosis, but I did not accept it and I went to another doctor. The acceptance process was very difficult. I cried constantly for a year."*											
2. Opinions on individual education	A1	A2	A3	A4	A5	B1	B2	B3	B4	B5	Total (n=10)
I feel good coming to the institution	x	x	x	x	x	x	x	x			8
A5: *"I go to the institution with hope every time, I never lose hope. Because the moment I lose hope, we are negatively affected."*											
I feel incomplete/guilty when we cannot come to treatment.	x	x	x	x			x	x		x	7
A2: *"I think that if we cannot go to treatment, my child's treatment will be negatively affected and I am not a good enough mother."*											
We get response from treatment	x	x	x	x	x		x			x	7
B2: *"We have been in this institution for 8-9 years, the treatment had positive aspects. You know, the treatment may last a lifetime, but the treatments are good."*											
I like to be involved in treatment		x			x	x				x	4
I make time for myself while my child is in session.	x		x		x		x	x	x		6
B1: *"I am always with the teachers during class. I ask at what angle I should do the movements, with what strength I should do them, how to protect my back and waist, everything."*											
3. Opinions about session times	A1	A2	A3	A4	A5	B1	B2	B3	B4	B5	Total (n=10)
Number of weekly sessions is insufficient	x					x	x	x	x		5
Number of weekly sessions is sufficient		x	x	x	x					x	5
B3: *"Our physiotherapist does the sessions very well, but it would be better if we could get more treatment."*											
4. Opinions about the person providing the education	A1	A2	A3	A4	A5	B1	B2	B3	B4	B5	Total (n=10)
I like our physiotherapist and find her/him adequate.	x	x	x	x	x		x	x			7
I think our physiotherapist needs to improve himself/herself						x			x	x	3
B4: "Our physiotherapist changes frequently, so we find it difficult to adapt to the treatment."											

themes; are opinions about disease diagnosis, opinions on individual education, opinions about session times, opinions about the person providing the education. The results of the semi-structured individual interviews are presented in Table 4.

DISCUSSION

The study observed that the GMFSS score, which is a measure of the child's level of functioning, had a negative effect on the family caregivers' PSQI and WHOQoL-BREF, but did not have a statistically significant effect on IoFS and PedsQL. Furthermore, a positive correlation was observed between PSQI and IoFS, while a negative correlation was evident between PSQI and WHOQoL-BREF.

A study comparing the caregiving burden of parents of children with CP and parents of healthy children found that parents of children with CP reported more negative experiences (30). In developing countries such as Turkey, mothers typically assume the primary caregiving role for children with CP (12,30). It has been demonstrated that this can result in a decline in physical health and sleep quality among mothers of children with CP (30).

Majnemer et al. reported that the impact of the disease on the family was not associated with sociodemographic characteristics, but was highly associated with low GMFCS level (31). The results of this study demonstrate that there is no statistically significant correlation between family involvement and either sociodemographic characteristics or the child's GMFCS level. The discrepancy in results between the aforementioned study and our own may be attributed to the fact that our study included a more limited population and a wider age range.

A review of existing studies has indicated that the quality of life of parents of children with CP is lower than that of parents of healthy children (12,32,33). However, the existing literature on the relationship between the GMFCS level of children with CP and the quality of life of mothers presents conflicting results. Some studies have indicated that this relationship is not statistically significant (30,34,35). The results of our study demonstrated a statistically significant negative correlation between the child's GMFCS level and the quality of life of the family caregivers. Additionally, there are studies in the literature that provide evidence to contradict the findings of our study (32,36). This can be attributed to the fact that children with low GMFCS levels require more assistance and support during their daily lives, which has a negative impact on their quality of life due to the additional burden on family caregivers.

In the existing literature, it has been reported that the quality of life of family caregivers may be affected by a number of factors, including the characteristics of their children, their own characteristics, environmental factors and/or their level of education (34,36). However, in contrast to the findings of previous studies, some research has indicated that there is no correlation between parental education level and the incidence of comorbidities in children, as well as the quality of life of the parents (19). When the results of our study were examined, it was seen that there was no correlation between the quality of life of the family caregivers and the education level of the family caregivers, the total number of siblings, and the child's concomitant illness. We also saw that the awareness of the family caregivers about the comorbidity was low and they primarily studied the dysfunctions caused by CP for the development of their children. Therefore, significant effects on quality of life may not have been observed.

A review of the literature on the sleep quality of parents with children with CP reveals that studies using similar methodologies have reported poor sleep quality in parents, with rates ranging from 71% to 40% (20,37,38). A total of 56.4% of caregivers who participated in the study reported poor sleep quality. This finding is consistent with previous research indicating that sleep problems are prevalent in caregivers of children with CP. It is crucial for healthcare professionals to recognise that this situation may have an impact on the treatment plan for the child.

It has been suggested that the level of satisfaction with the health services received by parents is an important factor in providing information about the quality and effectiveness of the treatment (39). A number of studies have indicated that having a greater number of children is positively correlated with parental satisfaction (9,39). The results of our study indicated that family caregivers with two children exhibited greater satisfaction than those with one child in the sub-parameters of family involvement and technical skill. This situation can be associated with the increase in satisfaction as the increasing number of children reduces the expectation from the treatment. Nevertheless, caregivers with two children exhibited greater satisfaction than caregivers with three or more children, as indicated by the PedsQL total score and sub-parameters pertaining to technical skill, emotional needs, and family involvement. This may be due to the fact that caregiver feel inadequate, due to the fact that having 3 or more children decreases the necessary care and attention on the child with CP. In our study, no significant relationship was found between health satisfaction and child GMFCS, family caregivers' quality of life and sleep quality.

When the literature was examined, it was seen that studies evaluating the education received by children with CP were insufficient. The various demographic characteristics of the family caregivers, their quality of life, sleep quality and the effects of the child with CP on the family; Considering that it may affect educational satisfaction, a comprehensive study was needed. In light of the aforementioned considerations, in addition to evaluating the caregivers with a survey, it was planned to detail the research data by conducting semi-structured individual interviews. As a result of the interviews, it was determined that the physiotherapist's professional competence and approach to the child are important factors affecting treatment satisfaction. They reported that family caregivers who trust their physiotherapists feel more comfortable, happier and feel responsible during the treatment process.

In order to enhance the quality of education provided, it is imperative that the satisfaction and expectations of caregivers, who play a pivotal role in the treatment process of the child, are not overlooked (40). We believe that the treatment process will be positively affected when the demands of the caregivers and their satisfaction with the treatment are questioned by conducting individual interviews at regular intervals.

Limitations of our study are that there was no control group consisting of family caregivers with healthy children and the child's sleep quality was not evaluated.

The findings of our study indicated that the physical dependence of the child had a detrimental impact on the quality of life and sleep of the family caregivers, as well as their satisfaction with the treatment. The number of siblings was also found to influence the family caregivers' satisfaction with the treatment. It is recommended that further information be obtained through semi-structured individual interviews regarding family caregivers' disease perceptions and IPE needs. Authors think that family caregivers' satisfaction will increase when healthcare professionals work in partnership with patients and families.

Sources of Support: This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

Conflict of Interest: The authors declare that they have no competing interests.

Author Contributions: Sare Hüsrevoğlu: Idea, Literature Review, Analysis and Interpretation, Materials, Article Writing, Sena Özdemir Görgü: Idea, Design, Critical Review, Analysis and Interpretation, Supervision, Devrim Tarakçı: Idea, Design, Data Collection and Processing

Explanations: This manuscript was produced from the master thesis, it has not been published elsewhere, in part or in entirety.

Acknowledgement: Authors are grateful to all the participants who voluntarily offered their time, conscientiously provided honest and thoughtful responses.

REFERENCES

1. Graham HK, Rosenbaum P, Paneth N, Dan B, Lin JP, Damiano DiL, et al. Cerebral palsy. Nat Rev Dis Prim. 2016;7(2):15082.
2. Smith M, Blamires J. Mothers' experience of having a child with cerebral palsy. A systematic review. J Pediatr Nurs. 2022;64:64–73.
3. Serdaroğlu A, Cansu A, Özkan S, Tezcan S. Prevalence of cerebral palsy in Turkish children between the ages of 2 and 16 years. Dev Med Child Neurol. 2006;48(6):413–6.
4. Dlamini MD, Chang YJ, Nguyen TTB. Caregivers' experiences of having a child with cerebral palsy. A meta-synthesis. J Pediatr Nurs. 2023;73(August):157–68.
5. Park E-Y. Validity and reliability of the caregiving difficulty scale in mothers of children with cerebral palsy. Int J Environ Res Public Health. 2021;18(11):5689.
6. Bastami L, Jahantabi-nejad S, Ghasemzadeh R, Akbari M, Dastoorpour M. Research article ınvestigating the predictive factors of life balance in mothers of children with cerebral palsy. J Mod Rehabil. 2024;18(1):76–83.
7. Testani DA, Hatherly K, Csercsics A, Pajak S. Caregiver stress and ımpact on children with cerebral palsy : A systematic review. Authorea. 2024;1–9.
8. Millî Eğitim Bakanlığı. Bedensel Yetersizliği Olan Bireyler İçin Destek Eğitim Programı [Internet]. 2024. Available from: https://ookgm.meb.gov.tr/meb_iys_dosyalar/2021_07/09102952_21130008_Bedensel.pdf
9. Cetintas I, Kostak Akgun M, Semerci R, Kocaaslan EN. The relationship between parents ' perceptions of family-centered care and their health care satisfaction. Eurasian J Fam Med. 2021;10(3):125–34.
10. Mohamed RA, Kamal HM, Gharib RM. Exploration of parental satisfaction with physical therapy services in pediatrics out-patient clinics. Egypt J Hosp Med. 2022;89(1):5386–91.
11. Michael-Asalu A, Taylor G, Campbell H, Lelea LL, Kirby RS. Cerebral Palsy: Diagnosis, Epidemiology, Genetics, and Clinical Update. Adv Pediatr [Internet]. 2019;66:189–208. Available from: https://doi.org/10.1016/j.yapd.2019.04.002
12. Paulson A, Vargus-Adams J. Overview of four functional classification systems commonly used in cerebral palsy. Child. 2017;4(4).
13. Palisano R, Rosenbaum P, Bartlett D, Livingston M. GMFCS. Handb Dis Burdens Qual Life Meas. 2007;4217–4217.
14. Stein RE, Riessman CK. The development of an impact-on-family scale: preliminary findings. Med Care. 1980;18(4):465–72.
15. Bek N, Engin IE, Erel S, Yakut Y, Uygur F. Turkish version of impact on family scale: A study of reliability and validity. Health Qual Life Outcomes. 2009;7(1):1–7.
16. Beydemir F. The Impact on Family Scale'ın (Aile Etki Ölçeği) Türkçe'ye uyarlanması, geçerlilik ve güvenilirliği. Pamukkale Üniversitesi Sağlık Bilimleri Enstitüsü Fizik Tedavi ve Rehabilitasyon Anabilim Dalı. 2008.
17. Aigner M, Förster-Streffleur S, Prause W, Freidl M, Weiss M, Bach M. What does the WHOQOL-Bref measure? Measurement overlap between quality of life and depressive symptomatology in chronic somatoform pain disorder. Soc Psychiatry Psychiatr Epidemiol. 2006;41(1):81–6.
18. Eser E, Fidaner H, Fidaner C, Eser SY, Elbi H, Göker E. WHOQOL-100 ve WHOQOL-BREF'in psikometrik özellikleri. Psikiyatr

Psikol Psikofarmakol Derg. 1999;7((Ek 2)):23–40.

19. Kizhakkethara V, Chathoth Meethal A. Self-efficacy and quality of life of mothers of children with cerebral palsy: the effect of multi ıntervention package. J Psychosoc Rehabil Ment Heal. 2022;9(3):275–82.
20. Lang CP, Boucaut A, Guppy M, Johnston LM. Children with cerebral palsy: A cross-sectional study of their sleep and their caregiver's sleep quality, psychological health and well-being. Child Care Health Dev. 2021;47(6):859–68.
21. Ağargün MY, Kara H, Anlar Ö. Pittsburgh uyku kalitesi indeksinin geçerliği ve güvenirliği. Türk Psikiyatr Derg. 1996;7.2:107–15.
22. Varni JW, Seid M, Kurtin PS. PedsQLTM 4.0: Reliability and validity of the Pediatric Quality of Life InventoryTM Version 4.0 Generic Core Scales in healthy and patient populations. Med Care. 2001;39(8):800–12.
23. Ulus B, Kublay G. PedsQL sağlık bakımı ebeveyn memnuniyet ölçeğinin Türkçe'ye uyarlanması. Acıbadem Üniversitesi Sağlık Bilim Derg. 2012;3(1):44–50.
24. Cetintas I, Kostak MA, Semerci R, Kocaaslan EN. The relationship between parents' perceptions of family-centered care and their health care satisfaction. Eurasian J Fam Med. 2021;10(3):125–34.
25. Balandin S, Hemsley B, Sigafoos J, Green V. Communicating with nurses: The experiences of 10 adults with cerebral palsy and complex communication needs. Appl Nurs Res. 2007;20(2):56–62.
26. Çay E. Ağır ve çoklu yetersizliğe sahip çocuğu olan ebeveynlerin evde eğitime ve çocuklarına yönelik gereksinimlerinin belirlenmesi. Yaşadıkça Eğitim. 2024;38(1):120–33.
27. Kalaycı Ş. SPSS uygulamalı çok değişkenli istatistik teknikleri. 9th ed. Ankara: Asil Yayın Dağıtım Ltd. Şti.; 2018. 426 p.
28. Yıldırım A, Şimşek H. Sosyal bilimlerde nitel araştırma yöntemleri. Seçkin Yayıncılık [Internet]. 2016;10. Available from: http://eku.comu.edu.tr/article/view/1044000129
29. Miles MB, Huberman AM. Qualitative data analysis: An expanded Sourcebook. Vol. 2, Sage. 1994.
30. Albayrak I, Biber A, Çalışkan A, Levendoglu F. Assessment of pain, care burden, depression level, sleep quality, fatigue and quality of life in the mothers of children with cerebral palsy. J Child Heal Care. 2019;23(3):483–94.
31. Majnemer A, Shevell M, Law M, Poulin C, Rosenbaum P. Indicators of distress in families of children with cerebral palsy. Disabil Rehabil. 2012;34(14):1202–7.
32. Glinac A, Matović L, Delalić A, Mešalić L. Quality of life in mothers of children with cerebral palsy. Acta Clin Croat. 2017;56(2):299–307.
33. Sonune SP, Gaur AK, Shenoy A. Prevalence of depression and quality of life in primary caregiver of children with cerebral palsy. J Fam Med Prim Care [Internet]. 2021;10:4205–11. Available from: http://www.jfmpc.com/article.asp?issn=2249-4863;year=2017;volume=6;issue=1;spage=169;epage=170;aulast=Faizi
34. Lee MH, Matthews AK, Park C. Determinants of health-related quality of life among mothers of children with cerebral palsy. J Pediatr Nurs. 2019;44:1–8.
35. Lee MH, Matthews AK, Park CG, Vincent C, Hsieh K, Savage TA. Relationships among parenting stress, health-promoting behaviors, and health-related quality of life in Korean mothers of children with cerebral palsy. Res Nurs Heal. 2020;43(6):590–601.
36. Farajzadeh A, Maroufizadeh S, Amini M. Factors associated with quality of life among mothers of children with cerebral palsy. Int J Nurs Pract. 2020;26:1–9.
37. Petersen S, Francis KL, Reddihough DS, Lima S, Harvey A, Newall F. Sleep problems and solution seeking for children with cerebral palsy and their parents. J Paediatr Child Health. 2020;56:1108–13.
38. Hulst RY, Gorter JW, Voorman JM, Kolk E, Van Der Vossen S, Visser-Meily JMA, et al. Sleep problems in children with cerebral palsy and their parents. Dev Med Child Neurol. 2021;63(11):1344–50.
39. Cimke S, Mucuk S. Mothers' Participation in the hospitalized children's care and their satisfaction. Int J Caring Sci. 2017;10(3):1643.
40. Mwinbam MM, Suglo JN, Agyeman YN, Kukeba MW. Family caregivers' experience of care with a child with cerebral palsy: The lived experiences and challenges of caregivers in a resource-limited setting in northern Ghana. BMJ Paediatr Open. 2023;7(1):1–10.