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Chronic fatigue syndrome in caregivers of children with cerebral palsy and affecting factors

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ABSTRACT

OBJECTIVE: In this study, the frequency of chronic fatigue syndrome (CFS), sleep disturbances, and quality of life levels in mothers of children with cerebral palsy (CP) was compared in relation to the functional status of the child.

METHODS: The caregivers were evaluated with the sociodemographic data form, Chalder fatigue scale (ChFS), Fatigue Severity Scale (FSS), Pittsburgh Sleep Quality Index, and Short Form-12, respectively. In addition, the functional status of the child with CP was evaluated with the gross motor function classification system, manual ability classification system (MACS), communication function classification system, and eating and drinking ability classification system.

RESULTS: According to CDC-1994 criteria, 80.4% of the participating mothers have CFS (n=45). While the mean ChFS and FSS scores of housewives were found to be significantly higher than those of full-time workers (p=0.002; p=0.003, respectively), the mean SF-12 MCS was found to be significantly lower (p=0.007). The rate of housewives was found to be significantly higher in those diagnosed with CFS (p<0.001). The relationship between independent variables and dependent variables data sets as a result of canonical correlation analysis was obtained as 0.815. While the variable with the highest effect among the independent variables is the MACS variable, the variable with the highest percentage of explanation for the dependent variables is ChFS.

CONCLUSION: The frequency of CFS is very high in mothers of children with CP, and the most important factors in the presence and severity of CFS are the mother's occupational status and the child's manual skills.

Keywords: Caregiver, cerebral palsy; chronic fatigue syndrome; quality of life; sleep quality.

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Children with cerebral palsy (CP) need constant and sensitive attention from their caregivers for safer and more effective treatment. Changes occur in family routines, particularly with a possible direct impact on the lives of mothers [1]. As a result of different studies on families with disabled children, it has been reported that especially the mother is more tired, anxious, and depressed, since the mother is the main person who takes care of the child [2, 3]. It has been shown that the severity of fibromyalgia increases in mothers of children with CP in relation to the functional level of the child [4]. Garip et al. [5] it has been reported that the fatigue levels of mothers with children with CP are higher than the controls, and it is associated with depression and worsening in quality of life in terms of functionality.

Chronic fatigue syndrome (CFS) is a chronic and difficult-to-treat disease lasting at least 6 months, with an unexplained cause, accompanied by musculoskeletal pain with fatigue, sleep disturbance, impaired concentration, and headache [6]. It was first defined as a con-

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spicuous disorder in 1988, with the classification made by the US Centers for Disease Control and Prevention (CDC) [7]. Later, on the emergence of many definitions, diagnostic criteria were published by the CDC in 1994 and then by the Institute of Medicine in 2015 [8, 9]. The 1994 criteria are still widely used. Although its prevalence is between 0.2 and 2.6% in the adult population, it is thought to be more common today because many patients cannot be diagnosed [10]. CFS does not have a mortal course despite high levels of physical and psychosocial discomfort and is a disabling disorder [11].

Seventy percentages of the cases diagnosed with CFS also meet the fibromyalgia criteria. Thirty to seventy percentages of patients with fibromyalgia meet the criteria for CFS. Patients with CFS are also prone to depression [12].

We believe that in a group where fibromyalgia is seen more frequently, CFS, which is characterized by fatigue, sleep disturbance, concentration disorder, and musculoskeletal pain, may also be seen more frequently in caregivers of disabled children. In this study, the frequency of CFS, sleep disturbances, and quality of life levels in mothers of children with CP were compared in relation to the functional status of the child.

Highlight key points

- The frequency of chronic fatigue syndrome is very high in mothers of children with cerebral palsy.
- The most effective factor on the severity of chronic fatigue, sleep quality and quality of life in the mother of the child with cerebral palsy is the child's manual dexterity.
- The most important determinants of chronic fatigue in the mother of a child with cerebral palsy are the child's manual skills and the mother's occupational status.

MATERIALS AND METHODS

The study included 56 CP patients aged 1–18 years and their primary caregivers.

The design of this study was an observational cross-sectional study conducted in accordance with the strengthening of the reporting of observational studies in epidemiology statement guideline in accordance with the Declaration of Helsinki.

Inclusion criteria were as follows; (1) having a child aged 1–18 with a diagnosis of CP, (2) the parent taken into consideration primarily caring for the child with CP, and (3) the caregiver has a literacy level that can understand the forms to be it was filled in. The exclusion criteria were as follows: (1) the emergence of CP as a result of brain lesions such as traumatic brain injury, (2) having low communication skills and not having a native Turkish language, and (3) other than the child with CP, the elderly and those with chronic diseases who are in need of parental care.

Ethical approval was obtained with the decision of the Goztepe Prof. Dr. Suleyman Yalcin City Hospital Clinical Research Ethics Committee on January 11, 2023, and the approval number was 0020. A face-to-face interview was held with the participants and an informed consent form was signed.

Data Collection

After written consent, caregivers were evaluated with the sociodemographic data form, Chalder fatigue scale (ChFS), fatigue severity scale (FSS), Pittsburgh Sleep Quality Index, and Short Form-12, respectively. In addition, the functional status of the child with CP was evaluated according to the ICF model. Detailed examination of the child was performed by a PM&R specialist [13].

In the sociodemographic data form, the participants' gender, age, body mass index (BMI), employment status, and monthly household income were questioned.

The gross motor function classification system (GMFCS) is a five-level classification system and was developed by Palisano et al. [14] in 1997. It is used to classify gross motor functions in children with CP. It focuses on self-initiated movements with an emphasis on sitting, relocation, and mobility. The most valuable criterion is that the differences between the levels are meaningful in daily life. Level I denotes better functional status, while Level V denotes the highest level of functional disability. The test has validity and reliability for the Turkish version [15].

Manual ability classification system (MACS) is a classification system that evaluates the hand-use skills of children with CP between the ages of 4–18 in their daily activities. Like GMFCS, MACS is based on five levels of evaluation. It assesses how the child holds objects alone and to what extent he/she needs help and adaptation while performing various functions using his/her hand in daily life. While measuring the overall holding capacity of objects, it does not take into account the individual function of the hands or the ability to grasp. It focuses on how the child holds objects suit-

able for his age, regardless of the difference in function between the two hands. Level I is at its best in dexterity, while Level V is at its most unsatisfactory [16]. The Turkish version and cultural adaptation were made by Akpinar et al. [17].

The communication function classification system (CFCS) evaluates daily communication performance in individuals with CP over five levels. It does not explain the underlying causes of conditions such as cognitive, motivational, physical, speech, hearing, and/or language problems. It evaluates all methods that affect communication performance such as speech, facial expressions, gestures, eye contact, facial expression, use of augmentative, and alternative communications. In this test, Level I denotes better condition while Level V denotes poorer condition [18].

The eating and drinking ability classification system (EDACS) is a classification system that evaluates the eating and drinking functions of patients after the age of three. The safety and efficiency of eating and drinking were scaled at five levels, while three levels of scaling were added to assess dysphagia. Leveling is made according to the variety of food eaten, the presence of coughing and retching while eating, and the control of the movement of food and liquid in the mouth [19]. The test has validity and reliability for the Turkish version [20].

ChFS is a questionnaire that evaluates the severity of fatigue, consisting of 11 items in total, with 7-item physical fatigue and 4-item mental fatigue sections. High scores indicate greater fatigue severity [21].

FSS consists of nine questions. Each question consists of 7 points. High scores indicate higher fatigue. The validity and reliability studies of the scale for Turkiye were carried out by Armutlu et al. [22].

Pittsburgh Sleep Quality Index (PSQI) is a questionnaire that evaluates the quality of sleep under seven domains that evaluate subjective sleep quality, sleep latency, sleep duration, habitual sleep efficiency, sleep disorders, use of sleeping pills, and deterioration in daytime functions. The scale total score is between 0 and 21. If the total score is 5 or more, sleep quality is considered poor. It was prepared by Buysse et al. in 1989 and the test has validity and reliability for the Turkish version [23, 24].

The SF-12 Brief Health scale was created by taking 12 different items of SF-36. In a study developed by the Institute of Health and published in the Journal of Medical Care in 1994, comparisons of SF-12 and SF-36 were made and it was reported that SF-12 is more efficient to use due to its easy and quick implementation. SF-12 has a physical (SF12-PCS) and mental (SF12-MCS) assessment scale for which regression analysis has been applied to the general population [25]. The test has validity and reliability for the Turkish version [26].

Statistical Analysis

The descriptive statistics of the qualitative variables in the study is given as numbers and percentages, and the descriptive statistics of the quantitative variables are given as mean, median, standard deviation, minimum, and maximum. Pearson chi-square test was used to compare group rates in terms of qualitative variables. The conformity of the quantitative variables to the normal distribution was examined with the Kolmogorov–Smirnov test. The Mann–Whitney U-test was used to compare the mean of two independent groups. Relationships between quantitative variables were evaluated with Spearman correlation analysis. For multivariate analyses, the scale scores were taken as the dependent variable linear regression analyses were performed and the effects of the independent variables were evaluated. Backward method was used in the model as a variable selection method. Canonical correlation analysis, which is an advanced statistical model, which is among the multivariate analysis methods, was used to evaluate the relationships between dependent and independent data sets. The model evaluates the relationship between two different multivariate datasets. In the study, canonical correlation analysis was carried out in order to understand the relationship between the two data sets and to define the related variables to evaluate the relationships between the mother's outcomes (dependent variables) and the independent variables that may be effective. This analysis describes only the correlated variables between the two datasets and filters out the unrelated variables. This is a useful model for understanding important relationships by eliminating the effects of redundant variables in the dataset. It allows the data to be interpreted in a meaningful way. As a result of canonical correlation analysis, correlation values, eigenvalue, loading and cross-loading values of dependent, and independent variables, explained variance values were calculated. The statistical significance level was taken as 0.05 in the calculations and IBM SPSS Statistics for Windows, Version 26 (Armonk, NY, IBM Corp) was used.

Table 1. Descriptive statistics for quantitative variables

	Mean	Median	SD	Minimum	Maximum
Age of child (year)	7.93	6.75	4.44	2.00	18.00
Age of mother (year)	36.87	35.50	8.23	24.00	62.00
BMI of mother	26.89	26.58	4.55	17.58	37.50
Monthly income (TL)	12142.85	100	4717.19	5000	30000
GMFCS	2.67	3.00	0.97	1.00	5.00
MACS	2.85	3.00	0.99	1.00	5.00
EDACS	2.87	3.00	0.99	1.00	5.00
CFCS	2.39	2.00	1.05	1.00	5.00
Chalder fatigue scale	18.19	19.00	4.65	11.00	26.00
Fatigue severity scale	5.78	6.66	1.48	1.00	7.00
Pittsburgh sleep quality index	7.91	8.00	3.55	1.00	15.00
SF-12 PCS	44.28	46.18	11.44	24.93	62.92
SF-12 MCS	42.93	44.81	12.11	16.54	57.98

SD: Standard deviation; BMI: Body mass index; TL: Turkish liras; GMFCS: Gross motor function classification system; MACS: Manual ability classification system; CFCS: Communication function classification system; EDACS: Eating and drinking ability classification system; SF-12 PCS: Short form-12 physical component score; SF-12 MCS: Short form-12 mental component score.

RESULTS

The table below contains descriptive statistics for quantitative variables (Table 1).

While 89.3% of the participating mothers were housewives (n=50), 10.7% were working in a full-time job (n=6).

According to CDC-1994 criteria, 80.4% of the participating mothers have CFS (n=45), and 19.6% have not (n=11).

The table below shows the correlation coefficient and p-values obtained as a result of examining the relationships between chronic fatigue, sleep quality, and quality of life scores and the related variables (Table 2).

While the mean ChFS and FSS scores of housewives were found to be significantly higher than those of full-time workers (p=0.002; p=0.003, respectively), the mean SF-12 MCS was found to be significantly lower (p=0.007). No significant difference was observed in terms of PSQI and SF-12 PCS mean scores (p=0.130; p=0.145, respectively).

Those diagnosed with CFS according to CDC-1994 criteria had significantly higher BMI, ChFS, FSS, PSQI mean scores, higher GMFCS, MACS, EDACS, CFCS mean values of children (p=0.030 for BMI; p<0.001 for other variables), and lower monthly income, SF-12 PCS, and MCS mean scores (p=0.004; p=0.008; p=0.018, respectively). There was no significant difference in terms of the mean age of child and mother (p=0.134; p=0.838).

The rate of housewives was found to be significantly higher in those diagnosed with CFS according to CDC-1994 criteria (p<0.001).

The tables below show the results of linear regression analysis. The backward method is used as a variable selection method and the results of the final model are given (Table 3).

Canonical Correlation Analysis Results

Relationship between independent variables (age of child, age of mother, monthly income, GMFCS, MACS, EDACS, CFCS, and BMI of mother) and dependent variables (ChFS, FSS, PSQI, SF-12 PCS, and SF-12 MCS) data sets as a result of canonical correlation analysis was obtained as 0.815. While the variable with the highest effect among the independent variables is the MACS variable, the variable with the highest percentage of explanation for the dependent variables is ChFS. When cross-loading loads are evaluated, the variable that has the strongest relationship with the dependent variables among the independent variables is the MACS score. Among the dependent variables, the variable with the highest

Table 2. Spearman correlation analysis between chronic fatigue, sleep quality and quality of life scores and the related variables

	Chalder fatigue scale	Fatigue severity scale	Pittsburgh sleep quality index	SF-12 PCS	SF-12 MCS
Age of child (year)					
r	0.261	0.197	0.117	-0.202	-0.072
p	**0.050**	0.146	0.389	0.135	0.599
Age of mother (year)					
r	-0.028	-0.175	-0.086	0.030	-0.050
p	0.836	0.197	0.529	0.825	0.713
BMI of mother					
r	0.151	0.058	0.220	-0.157	-0.178
p	0.267	0.672	0.103	0.248	0.190
Monthly income (TL)					
r	-0.280	-0.203	-0.256	0.336	0.210
p	**0.037**	0.134	0.056	**0.011**	0.121
GMFCS					
r	0.581	0.529	0.554	-0.446	-0.161
p	**<0.001**	**<0.001**	**<0.001**	**0.001**	0.237
MACS					
r	0.681	0.681	0.592	-0.320	-0.360
p	**<0.001**	**<0.001**	**<0.001**	**0.016**	**0.006**
EDACS					
r	0.570	0.505	0.492	-0.217	-0.287
p	**<0.001**	**<0.001**	**<0.001**	0.108	**0.032**
CFCS					
r	0.494	0.430	0.409	-0.185	-0.070
p	**<0.001**	**0.001**	**0.002**	0.173	0.610
Chalder fatigue scale					
r		0.789	0.571	-0.443	-0.329
p		**<0.001**	**<0.001**	**0.001**	**0.013**
Fatigue severity scale					
r			0.635	-0.394	-0.299
p			**<0.001**	**0.003**	**0.025**
Pittsburgh sleep quality index					
r				-0.584	-0.376
p				**<0.001**	**0.004**
SF-12 PCS					
r					0.249
p					0.065

BMI: Body mass index; TL: Turkish liras; GMFCS: Gross motor function classification system; MACS: Manual ability classification system; CFCS: Communication function classification system; EDACS: Eating and drinking ability classification system; SF-12 PCS: Short form-12 physical component score; SF-12 MCS: Short form-12 mental component score.

correlation with the independent variables is ChFS. While the percentage of the independent variables being explained by the variables within themselves is 35.9%, the percentage of being explained by the dependent variables is 23.8%. While the percentage of explanation of the dependent variables in themselves was 55.3%, the percentage of explanation by the independent variable set was 36.7% (Table 4).

TABLE 3. Linear regression analysis results

Model	Unstandardized coefficients		p	95.0% confidence interval for B	
	B	SE		Lower bound	Upper bound
ChFS					
(Constant)	11.452	2.343	<0.001	6.749	16.155
Age of child	0.177	0.093	0.063	-0.010	0.365
Working status	-3.240	1.350	0.020	-5.949	-0.530
MACS	2.313	0.505	<0.001	1.300	3.326
PSQI	0.293	0.142	0.044	0.008	0.577
FSS					
(Constant)	3.728	0.707	<0.001	2.309	5.147
Working status	-0.850	0.433	0.050	-1.718	0.019
MACS	0.578	0.164	0.001	0.249	0.907
PSQI	0.170	0.046	<0.001	0.078	0.262
PSQI					
(Constant)	5.423	2.445	0.031	0.518	10.328
SF-12 PCS	-0.107	0.032	0.002	-0.171	-0.042
FSS	1.245	0.247	<0.001	0.750	1.741
SF-12 PCS					
(Constant)	48.436	7.146	<0.001	34.090	62.781
GMFCS	-5.349	2.036	0.011	-9.437	-1.261
EDACS	3.982	1.935	0.045	0.098	7.866
SF-12 MCS	0.218	0.111	0.050	-0.004	0.439
PSQI	-1.341	0.429	0.003	-2.203	-0.479
SF-12 MCS					
(Constant)	18.896	10.490	0.078	-2.164	39.956
Working status	9.443	4.752	0.050	-0.098	18.984
GMFCS	5.811	2.436	0.021	0.921	10.700
EDACS	-6.310	2.207	0.006	-10.741	-1.878
SF-12 PCS	0.365	0.144	0.014	0.076	0.654

ChFS: Chalder fatigue scale; MACS: Manual ability classification system; FSS: Fatigue severity scale; PSQI: Pittsburgh sleep quality index; GMFCS: Gross motor function classification system; EDACS: eating and drinking ability classification system; SF-12 PCS: Short form-12 physical component score; SF-12 MCS: Short form-12 mental component score.

DISCUSSION

Mothers of children with CP face many problems in life. Davis et al. [27] defined the most common problems and presumably the possible causes of fatigue in mothers of children with CP: Lack of social support and care services, stress in marital relationships, limited freedom, lack of coping strategies, scarcity of time and energy for physical activities, sleep interruption, difficulty in employment, and financial burden. Therefore, in this study, we investigated the frequency and severity of CFS, sleep quality, and quality of life in mothers of children with CP and the factors affecting them.

Yilmaz et al. and Xia et al. reported the mean SF-36 PCS score around 52 and Yilmaz et al. reported MCS score as 51 and Xia et al. reported as 30 for caregiving mothers of CP [28, 29]. The SF-12 scores of this study group are lower than these scores. These results are as expected since the quality of life is expected to be lower in people with CFS and the rate of CFS was found to be very high according to CDC criteria in our study group (80.4%).

Walking and hand manual skills are among the most important parameters for the child to provide self-care and to be a self-competent individual. A re-

Table 4. Canonical correlation analysis results

Model	Correlation	Eigenvalue	Wilks statistic	p
	0.815	1.972	0.187	<0.001
Proportion of variance explained	Set 1 by self	Set 1 by set 2	Set 2 by self	Set 2 by set 1
	0.359	0.238	0.553	0.367
Variable	Loading		Cross loading	
Independent variables				
Age of child	-0.371		-0.303	
Age of mother	0.037		0.030	
Monthly income (TL)	0.501		0.408	
GMFCS	-0.801		-0.653	
MACS	-0.895		-0.729	
EDACS	-0.732		-0.596	
CFCS	-0.656		-0.535	
BMI of mother	-0.268		-0.218	
Independent variables				
ChFS	-0.944		-0.769	
FSS	-0.881		-0.718	
PSQI	-0.785		-0.640	
SF-12 PCS	0.613		0.499	
SF-12 MCS	0.324		0.264	

BMI: Body mass index, TL: Turkish liras; GMFCS: Gross motor function classification system; MACS: Manual ability classification system; CFCS: Communication function classification system; EDACS: Eating and drinking ability classification system; SF-12 PCS: Short form-12 physical component score; SF-12 MCS: Short form-12 mental component score; ChFS: Chalder Fatigue Scale; FSS: Fatigue severity scale, PSQI: Pittsburgh sleep quality index.

cent study investigated the relationship between quality of life and gross motor functions of the caregivers of CP with a large sample and reported that the SF-36 PCS and the GMFCS levels are related [30]. Eker and Tüzün also reported the same results between QoL of mother and GMFCS of children [31]. In this study, SF-12 PCS and GMFCS, SF-12 PCS, and MCS scores were correlated with MACS. In this study, similar to other studies, although the relationship between GMFCS and mother's quality of life was shown, the child's manual skills seem to have a higher effect on the caregiver's quality of life.

Considering all functional indexes, GMFCS, MACS, EDACS, and CFCS were correlated with ChFS, FSS, and PSQI of the mother. Furthermore, SF-12 PCS and MCS scores were correlated with ChFS, FSS, and PSQI. As a result of the linear regression analysis, it is seen that if the child has better manual skills and the mother has a full-time job, the mother's sleep quality is better, the CFS and severity are less, and if the child's gross motor functions and eating and drinking skills are better, the mother's quality of life is better. As a result of a study with a large sample size conducted in Iran, it was revealed that the factors affecting the low quality of life of mothers of children with CP were socioeconomic status, marital satisfaction, fatigue, and inadequate support from services [32]. Farajzadeh et al. [33] found a significant relationship between employment and quality of life in their study; working mothers had higher quality of life scores than non-working mothers. Likewise, in this study, the most important determinant of quality of life mental score was working status, as well as being one of the determinants of having CFS and severity of fatigue. Although the number of mothers working full-time was very small, it can be deduced that mothers who work full-time have less CFS, less severe fatigue, and better quality of life.

According to the results of the canonical correlation analysis, the parameter with the greatest effect on the severity of chronic fatigue, sleep quality, and quality of life was the child's hand skills. Upper extremity problems are seen in 80% of children with CP [34]. Some of these problems are muscle tone abnormality, muscle weakness, coordination disorder, and loss of motor control. Upper extremity problems negatively affect the functionality of children with CP and cause limitations in activity and social participation [34].

In reverse, ChFS was the parameter best explained by the age of the child and the mother, the mother's BMI, the mother's occupation, and the child's functional status. Therefore, we think that this questionnaire may be a good option for screening CFS in mothers with children with CP.

The strength of the study is that not only gross motor functions but also hand functions, eating and drinking and communication functions are discussed in this study. In addition, to the best of our knowledge, there is no other study investigating CFS in caregivers of disabled children. The canonical regression analysis is also one of the strengthening elements of the study. However, the most important limitation of our study is the small sample size. Furthermore, because the number of working mothers was very small, it may have affected the results of the study.

Conclusion

As a result of the study, the frequency of CFS is very high in mothers of children with CP, and the most important factors in the presence and severity of CFS are the mother's occupational status and the child's manual skills. Therefore, we believe that social steps should be taken regarding the employment of mothers, and rehabilitation programs that prioritize not only walking but also the manual skills of the child should be supported.

Ethics Committee Approval: The Istanbul Medeniyet University Goztepe Prof. Dr. Suleyman Yalcin City Hospital Clinical Research Ethics Committee granted approval for this study (date: 11.01.2023, number: 2023/0020).

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