Research Article/Araştırma Makalesi

THE DETERMINATION OF CARE BURDEN AND COMPASSION LEVELS OF PARENTS PROVIDING CARE TO PATIENTS WITH CEREBRAL PALSY[1]

SEREBRAL PALSİLİ HASTALARA BAKIM VEREN EBEVEYNLERİN BAKIM YÜKÜ VE MERHAMET DÜZEYLERİNİN BELİRLENMESİ

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ABSTRACT

The aim of the study is to determine the caregiver burden and compassion levels of parents who provide care to individuals with cerebral palsy. This cross-sectional study was conducted with 158 parents who provided care to individuals with cerebral palsy being followed at rehabilitation centers in Istanbul. Data were collected face-to-face using the Personal Information Form, the Caregiver Burden Scale, and the Compassion Level Scale Inquiry Form. It was found that those with a university education, those who could not cover the child's expenses, those who could not benefit from their spouse in the care of the child, and those who had no one other than their spouse to help in the care of the child had higher mean scores on both the Caregiver Burden Scale and the Compassion Scale, and the differences were statistically significant. It was found that those with the ataxic type of cerebral palsy and those with additional problems along with cerebral palsy had statistically significant higher mean scores on the Caregiver Burden Scale and the Compassion Scale. As a result, it is recommended that the care needs of parents who provide care to individuals with cerebral palsy be identified and that treatment be evaluated with a holistic approach.

ÖZET

Çalışmanın amacı; serebral palsili hastalara bakım veren ebeveynlerin bakım yükü ile merhamet düzeylerinin belirlenmesidir. Kesitsel tipteki çalışma İstanbul ilindeki rehabilitasyon merkezlerinde takip edilen serebral palsili hastalara bakım veren 158 ebeveyn ile gerçekleştirildi. Veriler, Kişisel Tanımlayıcı Form, Bakım Verme Yükü Ölçeği ve Merhamet Düzeyi Ölçeği Sorgulama Formu ile yüz yüze olarak toplandı. Araştırmaya katılan ebeveynlerden eğitim durumu üniversite olanların, çocuğun masraflarını karşılayamayan, çocuğun bakımında eşinden faydalanamayan, çocuğun bakımında eşinden başka yardım edeni olmayanların bakım verme yükü ölçeği ve merhamet ölçeği puan ortalamalarının daha yüksek ve aralarındaki farkın istatistiksel olarak anlamlı olduğu bulundu. Serebral palsi tipi ataksik tip olan, serebral palsi ile birlikte başka sorunu olanların Bakım Verme Yükü Ölçeği ve Merhamet Ölçeği puan ortalamalarının istatistiksel olarak anlamlı olduğu bulundu. Sonuç olarak, serebral palsili hastalarla beraber bakım veren ebeveynlerin de bakım ihtiyaçlarının belirlenerek tedavinin bütüncül yaklaşımla değerlendirilmesi önerilmektedir.

[1] This study was presented as an abstract at the 1. National Nuh Naci Yazgan Health Sciences Congress on 03-04 May 2024.

INTRODUCTION

Cerebral palsy (CP) is a non-progressive disorder characterized by movement and sensory impairments. As a neurodevelopmental disorder, it is the most common cause of disability in childhood, affecting motor, sensory, and/or cognitive functions (Xu, 2020). In addition to the existing condition, children with CP may experience urinary incontinence, feeding issues, intellectual disability, motor impairments, visual disturbances, and respiratory problems (Vitrikas, 2020). These issues, which affect all structures and functions, particularly increase the care burden and negatively impact the biopsychosocial health of the caregiver (Durà-Vilà, 2010; Maimani, 2019).

Care burden refers to the increased sense of pressure due to psychological, physical, social, and economic problems experienced by the caregiver, compounded by cognitive deficiencies (Jafari, 2018). Parents of individuals diagnosed with cerebral palsy spend most of their time providing care and performing activities to maintain daily living functions. Spending a significant amount of time on caregiving also necessitates restrictions in the social relationships of the parent (Park, 2019). Social isolation, economic problems, and sociocultural issues in the parent increase the pressure on the caregiver. This, in turn, lays the groundwork for psychological problems such as decreased living standards, burnout, depression, anxiety, and social isolation (Albayrak, 2019; Avşaroğlu, 2018; Lee, 2019; Naeem, 2018; Pelchat, 1999; Toledano-Toledano, 2018).

The attitude of the parent towards the care-needing child is crucial, but the level of compassion is equally important. The sense of compassion helps parents to be less affected by negative situations, strengthens their empathy, and enhances their decision-making mechanisms (Polat, 2017). The concept of compassion involves showing interest, sympathy, and care towards someone in distress or weakness, internalizing their suffering, experiencing their pain

together, approaching everyone with love, helping them in difficult times, protecting them from harm, and forgiving them (Gök, 2015).

Based on the definitions of compassion and fatigue, compassion fatigue can be considered the negative impact of helping individuals exposed to traumatic events (Dikmen, 2016). The problems associated with cerebral palsy reduce the quality of life for both the child and the caregiver. Therefore, early detection, intervention, and appropriate approaches to these problems are critical for both the child and the parent (Pruitt, 2009). The social, physical, economic, and psychological problems caused by the caregiving burden and compassion fatigue experienced by parents caring for children with cerebral palsy can adversely affect the caregiver's quality of life (Başaran, 2005; Özşenol, 2003). In Turkey, the prevalence of CP is 4.4 per 1,000 live births. This rate necessitates the evaluation of the health of both cerebral palsy patients and their parents (İçağasıoğlu, 2021). Considering all these issues, the spending on treating psychological problems alone by countries exceeds one trillion dollars (Sood, 2020). If the difficulties or feelings of inadequacy experienced by parents in caregiving are identified, psychological improvements can be made, preventing health issues and reducing treatment costs. Based on all these reasons, it is aimed to determine the care burden and compassion levels of parents who care for patients with cerebral palsy.

Previous studies have generally focused on variables such as stress, burnout, and quality of life among families caring for children with cerebral palsy (CP) in Turkiye; however, the simultaneous examination of caregiver burden and compassion levels remains limited. Compassion, beyond being mere empathy, is a critical factor in sustaining psychological resilience and managing burnout throughout the long-term caregiving process. Therefore, a holistic evaluation that considers both caregiver burden and compassion, encompassing the physical and emotional aspects of caregiving, is essential. This study aims to address this gap in the literature and make an original contribution by providing a comprehensive understanding

of these factors among caregiving families. This study aims to examine the relationship between caregiver burden and compassion levels among parents of children with cerebral palsy.

Research Questions

1. Which demographic variables are associated with differences in caregivers' perceived burden levels?

2. Do compassion levels among caregivers differ significantly based on demographic characteristics?

3. Is there a statistically significant correlation between caregiver burden and compassion levels?

4. Does the level of compassion significantly predict caregiver burden?

MATERIAL AND METHOD

Study Type

The study is a descriptive, cross-sectional study.

Population and Sampling

Our study was designed as a multicenter study and completed with CP patients and their parents' receiving treatment at rehabilitation centers in Istanbul. The participants in this study were parents who provided care for children diagnosed with cerebral palsy. In this study, participants were selected using a simple random sampling method to ensure representativeness of the target population. The required sample size was calculated using correlation analysis in the G*Power 3.1.9.4 software, with an assumed effect size of 0.3, α level of 0.05 (two-tailed), and a power ($1-\beta$ error probability) of 0.95. According to the results of the calculation, a minimum of 134 participants were needed. Consequently, the final analysis included data from 158 participants. The study included 158 parents who agreed to participate and the inclusion criteria.

Inclusion Criteria

Individuals diagnosed with cerebral palsy receiving care from their parents, parents aged 18 years or older who provide primary caregiving to a child with cerebral palsy, participants who have been involved in caregiving for at least 6 months, parents who voluntarily agree to participate and provide informed consent, participants able to communicate and understand the questionnaire language.

Exclusion Criteria

Parents of children with severe comorbid medical conditions that may independently affect caregiving burden, parents with diagnosed severe psychiatric disorders that might interfere with participation, participants who do not complete the data collection tools fully or withdraw consent.

Data Collection Tools

The study was conducted by face-to-face interview method between 08 October 2023 and 31 March 2024. The data of the study were collected by face-to-face interview methods using the Demographic Data Form, Care Burden Scale and Compassion Scale.

Demographic Questionnaire Form

This form includes questions about the parent's age, marital status, number of children, employment status, education level, ability to meet the child's treatment expenses, and spousal assistance in childcare. The section concerning the child includes questions about gender, age, weight, height, disability percentage, CP type, spasticity level, and additional health conditions.

Caregiver Burden Scale

The Zarit Caregiver Burden Scale (Burden Interview) was developed by Zarit and colleagues (1990) to assess the burden of parents of patients with dementia (Zarit et al., 1980). The Turkish validity and reliability study was conducted by İnci and Erdem (2008) (İnci & Erdem, 1980). The scale contains 22 items, each scored on a Likert scale from 0 to 4, with a total score ranging

from 0 to 88. Higher scores indicate a greater burden experienced by the caregiver. In our study, the Cronbach's Alpha internal consistency reliability coefficient was found to be 0.94.

The Compassion Scale

The Compassion Scale was developed by Pommier in 2011 (Pommier, 2011) and adapted to Turkish by Akdeniz and Deniz in 2016 (Akdeniz & Deniz, 2016). The scale comprises 24 items and six sub-dimensions: 'Kindness,' 'Indifference,' 'Common Humanity,' 'Separation,' 'Mindfulness,' and 'Disengagement.' The total score for the Compassion Scale is obtained by reverse scoring and summing all sub-dimensions. In cases where individual sub-dimensions are scored separately, reverse scoring is not performed. The scale is scored on a 5-point Likert scale, with a total score ranging from 24 to 120. Higher scores indicate higher levels of compassion. The Cronbach's Alpha internal consistency reliability coefficient for the entire scale was found to be 0.85 (Akdeniz & Deniz, 2016), and in our study, it was found to be 0.94.

Data Collection

The study data were collected through face-to-face interviews and survey forms. The scope of the study was explained to the parents responsible for the care of children with cerebral palsy. After obtaining informed consent, the survey questions prepared by the researchers were answered by the parents. Participants were informed that their personal information would not be shared with others, that they had full autonomy within the scope of the study, and that they could withdraw from the study at any time.

Data Analysis

The statistical analysis of the data was performed using the SPSS 22.00 statistical package program. Skewness and Kurtosis analyses were examined to assess the normality of distribution. The Skewness and Kurtosis values for the Caregiver Burden Scale and the Compassion Scale variables were within the normal range. Based on these results, the data were analyzed using Pearson Correlation Analysis, one-way ANOVA, Kruskal-Wallis H test, and

Mann-Whitney U test. Additionally, Linear Regression Analysis was applied to understand the predictive power of Caregiver Burden Scale scores on Compassion Scale scores.

Limitations of the Study

This study was conducted using data obtained from 158 voluntary participants between 08 October 2023 and 31 March 2024. The limitations of the study include the collection of data within a specific time frame and the relatively small sample size. In addition, the findings are constrained by the characteristics and scope of the measurement tools used, which may affect the generalizability of the results. Furthermore, the linear regression analysis examined only the effect of compassion levels on caregiver burden. Therefore, the findings should be interpreted within the context of this limitation. Future studies are recommended to employ models that include additional variables to gain a more comprehensive understanding of the factors influencing caregiver burden.

Ethical Committee Approval

Istanbul Esenyurt University Research Ethics committee permission from the board (Date: 07 October 2023, Number: 2023/08-29), institutional permission and research from the institution. It was carried out after obtaining the necessary permissions and approvals from the volunteers to participate. In research, permission was obtained for the scales to be used, and they are shown in the bibliography. This study was carried out in accordance with the Principles of the Declaration of Helsinki.

RESULTS

Of the parents who care for Cerebral Palsy patients included in the study, 86.7% are mothers, 43.7% are 31-40 years old, 93% are married, 37.3% have two children, 78.5% are unemployed, 39.2% are primary school graduates. 57% of them can cover the child's expenses, 69.6% benefit from their spouses in the care of the child, and 53.8% do not have anyone other than their spouse to help them in the care of their children (Table 1).

Table 1

Characteristics of Parents Caring for Children with Cerebral Palsy Included in the Study (n=158)

Variable	n	%
Parent		
Mother	137	86.7
Father	21	13.3
Age Mean ± SD= 37.94 ± 8.41 (Min-Max: 20-60)		
30 years and under	36	22.8
31-40 years	69	43.7
41 years and over	53	33.5
Marital Status		
Married	147	93.0
Single	11	7.0
Number of Children Mean ± SD= 2.34 ± 1.03 (Min-Max: 1-6)		
1 child	35	22.2
2 children	59	37.3
3 children	44	27.8
4 or more children	20	12.7
Employment Status		
Yes	34	21.5
No	124	78.5
Education Level		
Illiterate	9	5.7
Literate	29	18.4
Primary School Graduate	62	39.2
High School Graduate	41	25.9
University Graduate	17	10.8
Ability to Cover Child's Expenses		
Yes	90	57.0
No	68	43.0
Spouse's Assistance in Childcare		
Yes	110	69.6
No	48	30.4
Others Helping Besides Spouse in Childcare		
Yes	73	46.2
No	85	53.8

In the study; the mean scores of the Caregiving Burden Scale and Compassion Scale were found to be higher for those with a university education, parents who could not cover the child's expenses, parents who could not benefit from their spouses in the care of the child, and parents who did not assist in the child's care other than their spouses, and the difference between them was found to be significant at the $p<0.05$ level of significance (Table 1).

Table 1

Descriptive Characteristics of Children with Cerebral Palsy Included in the Study (n = 158)

Variable	n	%
Gender		
Female	76	48.1
Male	82	51.9
Age Mean ± SD= 8.31 ± 6.13 (Min-Max: 1–36)		
6 years and under	76	48.1
7–17 years	69	43.7
18 years and over	13	8.2
Body Mass Index (BMI)		
Underweight (≤ 18.5)	93	58.9
Normal weight (18.5–24.9)	51	32.3
Overweight (25–29.9)	13	8.2
Obese (≥ 30)	1	0.6
Type of CP		
Spastic type	116	73.4
Athetoid (dyskinetic) type	9	5.7
Ataxic type	12	7.6
Hypotonic type	21	13.3
Degree of Spasticity		
Mild	45	28.5
Moderate	60	38.0
Severe	53	33.5
Additional Conditions with CP		
Intellectual disability	72	45.6
Hearing problems	2	1.3
Vision problems	14	8.9
Epilepsy	22	13.9
Contracture	15	9.5
Other	33	20.9
Height Mean ± SD= 117.54 ± 25.42 (Min-Max: 63-170 cm)		
Weight Mean ± SD= 27.48 ± 16.93 (Min-Max: 6–95 kg)		
Disability Percentage Mean ± SD= 73.63 ± 17.79 (Min-Max: 20–99)		
Years Receiving Physical Therapy Mean ± SD= 6.64 ± 5.71 (Min-Max: 1–36)		

Caregiving Burden Scale, Affectionateness Dimension, Indifference Dimension, Awareness of Sharing Dimension, Disconnectedness Dimension, Conscious Awareness Dimension, Disconnection Dimension and Compassion Scale according to the gender, age, marital status, number of children and working status of the parents who care for patients with Cerebral Palsy (Table 2).

Table 2

Differences in the Caregiving Burden Scale and Compassion Scale according to the Descriptive Characteristics of the Parents who Care for Patients with Cerebral Palsy Included

	Caregiving Burden Scale	The Dimension of Being Aware of Sharings	Disconnection Dimension	Conscious Awareness Dimension	Disconnection Dimension	Compassion Scale
	Mean±SD	Mean±SD	Mean±SD	Mean±SD	Mean±SD	Mean±SD
Situation of benefiting from the spouse in the care of the child						
Yes	66.22±15.812	14.51±2.667	11.55±4.405	12.84±3.654	11.56±4.405	75.97±18.910
No	73.90±19.688	14.46±2.143	10.06±3.889	12.44±4.176	9.48±4.704	70.58±19.923
TEST	**t=-2.600 p=0.010**	t=0.116 p=0.907	**t=2.027 p=0.044**	t=0.604 p=0.547	**t=2.679 p=0.008**	t=1.621 p=0.107
The situation of having someone other than the spouse help in the care of the child						
Yes	65.00±16.124	14.26±2.398	10.63±3.889	12.03±3.682	10.21±3.965	71.07±17.936
No	71.60±17.933	14.69±2.605	11.51±4.605	13.31±3.842	11.55±4.996	77.14±20.117
TEST	**t=-2.416 p=0.017**	t=-1.082 p=0.281	t=-1.279 p=0.203	**t=-2.126 p=0.035**	t=-1.856 p=0.065	**t=-1.988 p=0.049**
Educational background						
Illiterate	78.78±19.791	13.22±2.906	8.44±3.358	11.33±4.528	9.89±5.231	65.11±22.877
Literate	71.55±15.032	14.76±2.340	9.72±4.008	11.69±3.828	9.10±4.585	68.24±19.634
Primary education	65.27±16.684	14.27±2.587	11.48±4.367	12.82±3.532	11.27±4.517	75.08±17.721
High school	69.10±19.018	14.54±2.111	11.54±4.501	12.71±3.983	11.32±4.424	76.37±19.869
University	68.65±17.051	15.41±3.063	12.41±3.726	14.82±3.414	12.41±4.388	82.00±18.762
TEST	KW=5.631	KW=5.633	**KW=9.564**	KW=8.934	KW=8.776	**KW=10.426**
Covering the child's expenses						
Yes						
No	-	-	**5>1-2**	-	-	**5>1-2**
TEST	62.42±16.44	14.03±2.633	11.30±4.156	12.50±3.826	11.12±4.370	73.94±18.514
	76.66±15.226	15.10±2.220	10.84±4.497	13.00±3.801	10.68±4.876	74.85±20.468
	t=-5.563 p=0.000	**t=-2.702 p=0.008**	t=0.667 p=0.505	t=-0.816 p=0.416	t=0.604 p=0.547	t=-0.292 p=0.771

In terms of the characteristics of the children with Cerebral Palsy included in the research; 51.9% are male, 48.1% are six years old and under, height arithmetic mean is 117.54±25.42, 58.9% are underweight, disability status arithmetic mean is 73.63±17.79, 73.4% have CP type Spastic type, physical therapy of the child. The arithmetic mean of the year seen was 6.64±5.71, 38% had moderate spasticity, and 45.6% had intellectual disability and hearing problems along with Cerebral Palsy.

When looking at the differences in terms of Caregiving Burden Scale and Compassion Scale scores according to the descriptive characteristics of patients with Cerebral Palsy; The chi-square value of the differences in the Caregiving Burden Scale scores of Cerebral Palsy patients according to their CP type and the Ataxic type individuals compared to the Spastic and Hypotonic group was found to be significant at the $p<0.05$ significance level (Table 3).

The chi-square values of the differences in terms of the Compassion Scale's Compassion Dimension, Indifference Dimension, Disconnectedness Dimension, Conscious Awareness Dimension, Disconnection Dimension and Compassion Scale total scores of patients with intellectual disability compared to whether patients with Cerebral Palsy have other problems along with Cerebral Palsy, $p<0.05$ significance. It was found to be significant at the level.

Differences in terms of Caregiving Burden Scale, Affectionateness Dimension, Indifference Dimension, Awareness of Sharing Dimension, Disconnectedness Dimension, Conscious Awareness Dimension, Disconnection Dimension and Compassion Scale scores of Cerebral Palsy patients according to their gender, age, BMI status and degree of Spasticity are at a significance level of $p>0.05$. was found meaningless (Table 3).

Table 3

Differences in Caregiving Burden Scale and Compassion Scale Scores According to the Descriptive Characteristics of Patients with Cerebral Palsy (n=158)

	Caregiving Burden Scale	The Dimension of Being Aware of	Disconnection Dimension	Conscious Awareness Dimension	Disconnection Dimension	Compassion Scale
	Mean±SD	Mean±SD	Mean±SD	Mean±SD	Mean±SD	Mean±SD
CP type						
Spastic type	66.91±17.204	14.39±2.679	11.02±4.364	12.61±3.865	11.09±4.659	74.13±19.533
Athetoid (dyskinetic) type	79.56±12.340	14.44±1.236	9.44±3.575	12.67±3.391	8.11±3.551	68.22±17.232
Ataxic type	80.58±13.794	13.75±2.094	10.42±4.621	11.58±4.166	9.33±4.313	67.75±18.266
Hypotonic type	66.05±18.467	15.52±1.940	12.67±3.812	13.95±3.398	12.14±4.258	81.86±18.213
TEST	**KW=11.752 p=0.008**	KW=7.299 p=0.063	KW=4.736 p=0.192	KW=3.183 p=0.364	KW=6.869 p=0.076	KW=5.759 p=0.124
DIFFERENCE	**3>1-4**	-	-	-	-	-
Presence of other problems along with Cerebral Palsy						
Intellectual disability	70.19±16.873	14.25±2.287	10.08±4.017	11.74±3.875	9.78±4.355	68.88±17.212
Hearing	94.50±7.778	13.00±1.414	5.50±0.707	10.00±4.243	6.00±1.414	50.00±5.657
Seeing	63.57±18.438	14.21±2.778	11.00±3.803	12.29±3.384	11.86±4.276	73.93±19.558
Epilepsy	65.64±17.821	14.59±2.840	12.32±4.379	13.59±3.446	12.00±4.751	79.50±19.471
Contracture	74.73±15.526	14.60±2.720	11.73±4.713	12.80±2.783	11.13±4.406	75.73±17.609
Other	64.64±17.275	15.12±2.631	12.61±4.337	14.58±3.841	12.55±4.678	83.82±20.423
TEST	KW=10.282 p=0.068	KW=2.796 p=0.731	KW=14.889 p=0.011	KW=14.417 p=0.013	KW=13.590 p=0.018	KW=18.219 p=0.003
DIFFERENCE	-	-	3-4-5-6>2 4-6>1	6>1	6>2 4-6>1	3-4-5-6>2 4-6>1

Pearson correlation analysis was applied to understand whether there was a relationship between the Caregiving Burden Scale and Compassion Scale scores (Table 4).

Table 4

Arithmetic Mean and Standard Deviation Values for Caregiving Burden Scale and Compassion Scale Scores (n=158)

	Mean	Std. Deviation
Caregiving Burden Scale	68.55	17.38
Compassionate Dimension	13.34	4.04
Indifference Dimension	11.75	3.99
The Dimension of Being Aware of Sharings	14.49	2.51
Disconnection Dimension	11.10	4.30
Conscious Awareness Dimension	12.72	3.81
Disconnection Dimension	10.93	4.59
Compassion Scale	74.34	19.32

While the correlation values between the scores of the Caregiving Burden Scale and the Affectionateness Dimension of the Compassion Scale, the Indifference Dimension, the Disconnectedness Dimension, the Conscious Awareness Dimension, the Disconnection Dimension and the total scores of the Compassion Scale are all significant in the reverse direction at the $p<0.05$ significance level, the correlation value between the Awareness of Sharing Dimension scores. It was found to be insignificant at the $p>0.05$ significance level (Table 5).

As a result, it was determined that as the scores of the Caregiving Burden Scale increased, the total scores of the Compassion Scale's Affectionateness Dimension, Indifference Dimension, Disconnectedness Dimension, Conscious Awareness Dimension, Disconnection Dimension and Compassion Scale decreased (Table 5).

Table 5

Correlation Values Regarding the Relationship Between Caregiving Burden Scale and Compassion Scale Scores (n=158)

		Caregiving Burden Scale
1- Compassionate Dimension	r	-0.375
	p	p<0.001
2- Indifference Dimension	r	-0.425
	p	p<0.001
3- The Dimension of Being Aware of Sharings	r	-0.053
	p	0.508
4- Disconnection Dimension	r	-0.439
	p	p<0.001
5- Conscious Awareness Dimension	r	-0.349
	p	p<0.001
6- Disconnection Dimension	r	-0.413
	p	p<0.001
7- Compassion Scale	r	-0.438
	p	p<0.001

Linear Regression analysis was applied to understand the predictive power of the Caregiving Burden Scale scores on the Compassion Scale scores. Regression analysis was performed using the enter method. (Table 6).

Caregiving Burden Scale scores show significant relationships with the Compassion Scale (R=0.438 R^2=0.191 p<0.05). Caregiving Burden Scale variables explain 19% of the total variance of the Compassion Scale scores. When the t test results regarding the significance of the regression coefficients are examined, it is seen that the Caregiving Burden Scale variable is a significant predictor on the Compassion Scale scores (Table 6).

Since the VIF value for the variables Caregiving Burden Scale scores and Compassion Scale scores are 1.26, it indicates the absence of multicollinearity. Additionally, as the Durbin-Watson statistics are close to 2, it can be concluded that there is no autocorrelation (Table 6).

Table 6

Linear Regression Analysis Results Regarding the Prediction of Caregiving Burden Scale Scores on Compassion Scale Scores (n=158)

Variable	B	Standart Error	Beta	t	p
Constant	107.674	5.658		19.031	0.000
Caregiving Burden Scale	-0.486	0.080	-0.438	-6.078	0.000
R=0.438	Adj. R^2=0.186		Durbin Watson=1.472	VIF=1.26	
R^2=0.191					
F$_{(1.156)}$=36.941	p=0.000				

B: Unstandardized coefficient   t: t-value   p: Significance level   R: Correlation coefficient   R²: Coefficient of determination   Adj. R²: Adjusted R²   F: ANOVA test statistic   VIF: Variance Inflation Factor   DW: Durbin-Watson statistic

DISCUSSION

The care difficulty, dependency burden, and extensive time commitment involved in caring for children with cerebral palsy (CP) impact parents physically, socially, psychologically, and economically (Tagher & Knapp, 2020). While it is commonly assumed that caregiving demands decrease as a child grows, the multiple challenges faced by children with CP, including their inability to perform self-care tasks, can increase the perceived caregiving burden on parents (Törüner & Büyükgönenç, 2013). Our study aimed to determine the caregiving burden and compassion levels among parents caring for children with cerebral palsy.

The mean age of the parents included in the study was 37.94 ± 8.41 years. Comparable studies in literature report similar findings. Yörük (2021) found the mean age of mothers of children with cerebral palsy to be 35.9 ± 8.6 years in relation to caregiving burden. Similarly, Piştav and Akmeşe (2016) reported a mean age of 31.41 ± 5.84 years for mothers providing care to children with cerebral palsy. Turğut (2019) noted that 54% of mothers caring for children with cerebral palsy were aged between 30 and 39 years. Furthermore, a study assessing

caregiving burden among parents of children with cerebral palsy reported a mean parental age of 35.57 ± 6.74 years (Turğut, 2016), corroborating our findings.

In our study, the mean score on the Caregiver Burden Scale was 68.55 ± 17.38. Similarly, Yıldırım reported a mean caregiver burden score of 62.58 ± 5.63 among parents of children with cerebral palsy (Yıldırım, 2020). In contrast, Erdem evaluated caregiving burden among caregivers of stroke patients and found a mean score of 34.30 ± 17.42, with 45.4% experiencing a moderate level of burden (Erdem, 2019). Günbeği, who examined the burden of mothers providing home care to children receiving treatment, reported a mean score of 52.42 ± 8.74 on the Caregiver Impact Scale (Günbeği, 2022).

According to our results, the mean Compassion Scale score for parents of children with CP was 74.34 ± 19.32. Emir et al., in a study on caregiver burden and compassion fatigue in mothers of children with special needs, reported a Compassion Fatigue score of 101.94 ± 11.98 (Emir et al., 2020). Similarly, Avşaroğlu and Güleş found a compassion level of 96.79 ± 13.405 in their study on life satisfaction, self-compassion, and compassion levels among parents of children with special needs (Avşaroğlu & Güleş, 2019).

The mean score of the Compassion Scale was found to be 74.34 ± 19.32, and the mean score of the Caregiver Burden Scale was 68.55 ± 17.38. When examining the differences according to the demographic characteristics of parents caring for children with cerebral palsy, it was found that parents with a university education, those who could not meet the child's expenses, those who did not receive help from their spouse in caregiving, and those who had no other assistance besides their spouse had higher mean scores on both the Caregiver Burden Scale and the Compassion Scale, with the differences being statistically significant at the $p<0.05$ level.

When examining the differences according to the demographic characteristics of children with cerebral palsy, it was found that children with the Ataxic type of CP and those with additional problems besides cerebral palsy had statistically significant differences in their total

scores on the Caregiver Burden Scale and the Compassion Scale with the differences being statistically significant at the p<0.05 level.

According to the educational status of parents caring for children with cerebral palsy, the chi-square values for differences in the Disconnection Dimension of the Compassion Scale and the total scores of the Compassion Scale were found to be statistically significant at the p<0.05 level. A Post Hoc test was applied to understand the source of the difference, revealing that parents with a university education had higher mean scores on the Disconnection Dimension and the Compassion Scale compared to illiterate parents and those with basic literacy, with the differences being statistically significant at the p<0.05 level.

This study determined that the education level of caregivers affects the caregiving burden, with higher education levels correlating with increased caregiving burdens, a finding that supports the literature. According to Sıkılmaz (2018), caregivers with high school education and above had higher compassion levels compared to other education groups (Sıkılmaz, 2018). Similarly, Arkan et al. (2020) found that nurses with postgraduate education had higher compassion levels (Arkan et al., 2019). In contrast, Özan (2019) found no relationship between education level and compassion level (Özan, 2019).

According to parents' ability to cover the expenses of their children with cerebral palsy, the t-values for differences in the Awareness of Shared Suffering dimensions of the Compassion Scale and the Caregiver Burden Scale were statistically significant at the p < 0.05 level. As shown in the table, caregivers who were unable to meet the child's expenses had higher mean scores on both the Caregiver Burden Scale and the Awareness of Shared Suffering dimension compared to those who could meet the expenses. These findings indicate that caregivers with financial difficulties experience greater caregiving burdens than other income groups. This result is consistent with previous studies reporting that individuals with lower socioeconomic status face increased caregiver burden (Çeler et al., 2018; Karcı et al., 2018; Polat, 2016; Tosun

et al., 2015; Yeşil et al., 2016). Türkmen et al. (2016) also noted that limited economic resources negatively impact caregiving burden due to restricted access to healthcare services (Türkmen et al., 2016). In contrast, some studies have reported no significant relationship between income level and compassion (Çingöl et al., 2018; İşgör, 2017; Seven et al., 2019).

According to the ability of parents of children with cerebral palsy to receive help from their spouse in caregiving, the t-values for differences in the Disconnection Dimension and the Separation Dimension of the Compassion Scale and the Caregiver Burden Scale were found to be statistically significant at the $p < 0.05$ level. Examination of the table shows that caregivers who did not receive help from their spouse had higher mean scores on the Disconnection Dimension and the Separation Dimension of the Compassion Scale and the Caregiver Burden Scale compared to those who received help from their spouse.

According to the presence of additional help besides the spouse in caregiving for children with cerebral palsy, the t-values for differences in the Mindful Awareness Dimension of the Compassion Scale and the total scores of the Compassion Scale and the Caregiver Burden Scale were found to be statistically significant at the $p < 0.05$ level. Examination of the table shows that caregivers who had no additional help besides their spouse had higher mean scores on the Mindful Awareness Dimension of the Compassion Scale and the total scores of the Compassion Scale and the Caregiver Burden Scale compared to those who had additional help.

Similar to our study results, Çalışır et al. (2018) found that mothers who had other individuals responsible for caregiving had a high caregiving burden mean score of 45.59 ± 10.73 (Çalışır et al., 2018). Similarly, Erdem (2019) found that receiving help from another individual during caregiving affected the caregiving burden and compassion level in caregivers of stroke patients (Erdem, 2019). This suggests that the high caregiving burden is influenced by mothers being the primary responsible caregivers due to cultural structure. Contrary to our findings, Yörük et al. (2021) found no statistically significant difference between the presence

of other responsible individuals and the caregiving burden scores in their study examining caregiving burden and influencing factors in mothers of children with cerebral palsy (Yörük, 2021).

The chi-square value for differences in the Caregiver Burden Scale scores according to the type of CP in children with cerebral palsy was found to be statistically significant at the $p<0.05$ level. A Post Hoc test was applied to understand the source of the difference, revealing that children with the Ataxic type of CP had higher mean scores on the Caregiver Burden Scale compared to those with Spastic and Hypotonic types of CP, with the differences being statistically significant at the $p<0.05$ level.

Contrary to our study results, Günbeğ (2022) found no significant relationship between the type of CP and caregiving burden in mothers of children with cerebral palsy receiving home or center-based treatment (Günbeğ, 2022). Another study examining the functional adequacy of children with CP and the depression and anxiety levels of mothers found no significant relationship between the type of CP and the mother's depression level (Khan et al., 2021).

CONCLUSION

A significant relationship was determined between Caregiving Burden and Compassion level in the opposite direction. Individuals with Cerebral Palsy are supported in social and health aspects. However, the parents responsible for their care do not have any support system. Ignoring one's own health problems with the instinct of being a parent and taking on lifelong care creates a great risk for the physical and mental health of individuals, and the increase in the level of commitment causes the quality of life to decrease. As a result, it is recommended that the care needs of the parents of patients with cerebral palsy as well as the care needs of the parents should be determined in the care plan to be applied and the treatment should be evaluated with a holistic approach.

ETHICAL COMMITTEE APPROVAL

The study was carried out with the approval of Istanbul Esenyurt University Ethic Committee (Date: 07 October 2023, Approval Number E-12483425-299-35745).

AUTHOR CONTRIBUTION

Idea/concept: İK, NTŞ; Design: İK, NTŞ; Consultancy: İK, NTŞ; Data collection: İK, NTŞ; Data Processing: İK, NTŞ; Analysis and/or Interpretation: İK, NTŞ; Literature review: İK, NTŞ; Writing of the article: İK, NTŞ; Critical review: İK, NTŞ.

CONFLICT OF INTEREST

The authors declare that they have no conflict of interest.

FINANCIAL DISCLOSURE

This study has not been financed by any institutional organization.

PEER REVIEW

Externally peer-reviewed.

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