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Comparison of the caregiver burden of the mothers of children with cerebral palsy and healthy children

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Abstract
The study aims to compare caregiver burden levels of mothers of children with cerebral palsy (CP) to mothers with healthy children. Methods: Participants comprised 40 mothers of children with CP (Group 1), and controls comprised 40 mothers with healthy children(Group 2). Caregiver burden inventory (CBI), hospital anxiety depression scale (HADS) were applied. The functional status of children with CP was evaluated by the Gross Motor Function Classification System (GMFCS). Secondary problems accompanying CP were also noted. Results: A secondary problem was seen in 75% of children with CP. The caregiver burden (CB) and the frequency of depression among Group 1 mothers were significantly higher than Group 2 mothers ($p<0,001$). CB was found to be higher in children with CP with poor functional status. The CB of caregivers in children with CP with secondary problems was significantly higher than the mothers of children without secondary problems ($p<0.05$). Conclusion: CP causes a higher burden on care for mothers than on healthy children, and at the same time, more frequent depression is observed in these mothers. Long-term prospective studies are needed to investigate the possible effects of the time shift in the functional status of patients with CP on the CB.

Keywords: Cerebral palsy, children, mother, caregiver burden

Introduction

According to Zarit, the person who undertakes the care of an individual who is inadequate in performing daily activities due to physical or mental illness is called caregiver [1]. The decrease in the frequency of death of people and the prolongation of the average life expectancy caused an increase in the number of individuals who need care [2,3]. The caregiver may vary with socio-cultural conditions. However, the care of patients is often undertaken by one of the family members or the patient's husband or wife [4].

Maintenance is usually not limited to a single kind of help. It also includes health care of the patients (medication use, treatment, follow-up, etc.), personal care (washing, feeding, toileting, living in the same house [1,3]. In Turkish society, care services are often given by family members. Caregiving has positive contributions such as increased emotional communication with the dressing, etc.), organizing the patient's social services, shopping, and domestic work, money management, financial support and patient, personal development, development of close relationships, social support from other individuals, self-esteem, and personal psychosocial satisfaction. However, there are many negative and difficult aspects [3,5,6].

Caregiver Burden (CB) is expressed as a multidimensional response related to caregiving, including physical, psychological, emotional, social, and economic problems [7]. Depression and anxiety may both affect the caregiver's quality of life and indirectly affect the care of the patient [4,8].

Cerebral Palsy (CP) is a permanent neurological disorder that is common in childhood, affecting movement and posture throughout life [9]. Many additional problems may accompany motor retardation. Sensory (vision, hearing problems), cognitive (mental retardation), communication (speech disorder), perception (such as lack of attention) problems, incontinence, difficulty in swallowing, and epilepsy are the most common accompanying problems [10]. The incidence of cerebral palsy in the world was reported 2-2.5 per 1000 live births [11], while in Turkey, it was reported as 4.4 per

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1000 live births in the most comprehensive study [12].

Functional limitations due to physical, mental, emotional, and social disorders of children with CP prevent them from fulfilling their roles in the society they live in [13,14]. The families of children with CP, especially their mothers, spare much less time and pay attention to themselves and if exists, to their children because children with CP are in need of constant care, have more frequent health problems, have more frequent follow-ups, and need regular and continuous physiotherapy, and also because caregivers assume the role of the child with their roles in society. For these reasons, the quality of life of family members who care for children with CP is also negatively affected [13,15-17].

In this study, we aimed to examine the caregiver burden, depression, and anxiety levels of mothers of children with CP and compare them with mothers with healthy children.

Material and Methods

Patients

This cross-sectional study was carried out between March 2018 and October 2018 with the mothers of patients with CP who were being treated at the local hospital Physical Medicine and Rehabilitation Service. Approval was obtained from the local ethics committee before starting the study. Written consent was obtained from the mothers who agreed to participate. Mothers of children without any chronic physical or psychiatric problems were contacted through a study brochure and posters on social media.

The inclusion criteria of the mothers of children with CP (Group 1) were; having a child with CP and living with the child, lack of a chronic psychiatric disorder, and the inclusion criteria of the mothers with healthy children (Group 2) were; inclusion criteria, having children without any chronic health problems and living together. Exclusion criteria were; using antidepressant and anxiolytic drugs that affect depression and anxiety scales, caring for another patient or disabled person with a child with CP, and the existence of any obstacle that will negatively affect the activities of daily living.

Demographic data, age, gender, CP type, additional problems, and functional status of children with cerebral palsy were evaluated and noted to the related form. Age, education level, marital status, the total number of children, and income levels of the mothers were questioned in both groups.

Scales

Children with CP were categorized by Swedish classification. According to this classification, the children are classified as; spastic (diplegic, quadriplegic and hemiparetic), ataxic, dyskinetic (including athetosis and dystonia), and mixed types [18]. To define functional levels, Gross Motor Function Classification System (GMFCS) was used in individuals with CP. GMFCS is a classification system rated between levels 1 and 5. A patient at Level 1 can walk comfortably indoors and outdoors without the need for assisting devices, while a patient at level 5 completely beds dependent. The difference between levels is determined by functional constraints and the use of assisting devices [19,20].

The effect of the chronic disease on the caring mother and the mothers coping with this condition were evaluated by the caregiver burden (CB) inventory. This scale was developed in 1989 by Novak and Guest in Canada [21], its validity and reliability studies were conducted in Turkey in 2009 and was published under the name of Caregiver Burden Inventory by Küçükgüçlü [22]. CB is a 24-item inventory developed to determine the caregiving burden of relatives of patients with cognitive impairment. CB, based on the view that the burden of caregivers is multidimensional, consists of five sub-factors; the time-dependency burden (TDB), developmental burden (DB), physical burden (PB), social burden (SB) and emotional burden (EB). While FD consists of 4 items and the other four factors consist of five items, each factor can get a minimum of 0 to a maximum of 20 points, and the total load score varies between 0 and 100. As the score from the inventory increases, the burden of the caregiver is increasing too. Inventory is a comprehensive tool suitable for use in both clinics and research [22].

The Hospital Anxiety and Depression Scale (HADS), developed by Zigmond and Snaith, is a quadruple Likert-type scale developed to determine the risk of anxiety and depression in individuals and to measure the level of depression and anxiety. The HADS scale consists of 14 items, 7 of which search depression symptoms (even numbers), and 7 of which search anxiety symptoms (odd numbers) [23-24]. The reliability and validity of the Turkish version were performed by Aydemir, and the scale was found to be dependable in terms of screening for symptoms of depression and anxiety in patients with physical illness. There are subscales of the scale for anxiety (HAD-A) and depression (HAD-D). The lowest score that patients and caregivers can take from both subscales is 0, and the highest score is 21. In the study conducted in Turkey, cut-off scores for anxiety subscale was 10, and for the depression subscale, it was 7. Based on this result, those scores above these are considered to be at risk.

Statistical Methods

SPSS 22 software was used for statistical analysis. Descriptive statistical findings were given as mean ± SD. Student t and chi-square tests were used to compare the parameters. The statistical significance and confidence interval were accepted as <0.05 and 95%, respectively.

Results

Forty mothers, who gave care to the children with cerebral palsy(Group 1), and 40 mothers with healthy children (Group 2) between 3-13 years were included in the study after informed consent was taken. Table 1 shows the sociodemographic data of each group of mothers, including age, education level, income level, marital status, number of children, and occupational groups. There was no significant difference between the two groups ($p>0.05$).

The mean ages of children with cerebral palsy and healthy children were similar (7.6±3.2, 6.8±2.6, respectively). 60% of children with cerebral palsy and 55% of healthy children were female. There was no significant difference determined between healthy children and children with CP ($p>0.05$).

Table 1. Baseline demographic data of groups

	Group 1	Group 2	P value
Mother Age Mean ± SD	34.92±6.1	33.02±5.3	>0.05
Marital Status (n (%)			
Married	40 (100%)	38 (95%)	>0.05
Other	0(%0)	2(5%)	
Education level (N (%))			
Illiterate	1(2.5%)	2(5%)	
Primary Education	22 (55%)	24 (60%)	>0.05
High school	14(35%)	10(25%)	
College Education	3 (7.5%)	4(10%)	
Occupation N(%)			
Housewife	32 (80%)	31 (77.5%)	
Worker	1(2.5%)	4(10%)	>0.05
Officer	6 (15%)	4(10%)	
Other	1(2.5%)	1(2.5%)	
Number of Children (Mean ± SD)	2.32±0.8	2.30±0.7	>0.05
Income Level (N (%))			
Poor	5(%12.5)	4(10%)	>0.05
Moderate	26 (65%)	28 (70%)	
Good	9 (22.5%)	8(%20)	

SD Standart Deviation

The distribution percentages of patients according to Swedish classification ; 17 patients (42.5%) were spastic diplegic, 9 (22.5%) were spastic tetraplegic, 8 (20%) were spastic hemiplegic, 3 (7.5%) were dyskinetic, and 3 (7.5%) were mixed type. We didn't have hypotonic CP patients.

GMFCS scores of children with cerebral palsy are shown in Table 2. While 30% of the patients were bed-dependent (Stage 5), only one (2.5%) patient was able to walk independently.

Table 2. GMFCS Scores of Children with CP

GMFCS	Number	Percentage
Level 1	1	2.5
Level 2	14	35
Level 3	10	25
Level 4	4	10
Level 5	11	27.5

GMFCS Gross Motor Function Classification System, CP Cerebral Palsy

In 75% of patients (30) with cerebral palsy, secondary problems were present except movement disorder. The most common additional problems and their frequencies are monitored as; epilepsy (25%), mental problems (17.5%), communication and hearing problems (17.5%), incontinence (15%), eating disorders (10%), visual problems (7.5%).

The HADS total scores of the mothers of children with cerebral palsy were 16.25±7.09, the HADS total scores of the mothers with healthy children were 14.5±6.39, and there was no statistically significant difference between these groups (Table 3, p>0.05). The number of mothers, who scored higher than the cut-off value, which was accepted as anxiety [11], was higher in mothers of children with CP, but this difference was not statistically significant (p> 0.05). The number of mothers, who scored higher than the cut-off value, which was accepted as depression [7], was higher in mothers of children with CP, and the difference between the two groups was statistically significant (p <0.05).

Table 3. Comparison of HADS Measurements and Anxiety-Depression Frequencies

	Group 1	Group 2	P value
HADS Total	16.25±7.0	14.5±6.3	p>0.05
HADS Anxiety score	8.3±4.1	7.82±3.2	p>0.05
HADS Depression Score	7.92±3.8	6.62±3.6	p>0.05
Anxiety N(Percentage)			
Yes	15 (37.5%)	10 (25.0%)	p>0.05
No	25 (62.5%)	30 (75.0%)	
Depression N(Percentage)			
Yes	21 (52.5%)		* p = 0.041
No	19 (47.5%)		

HADS Hospital anxiety and depression scale

The mean total score of caregiver burden was significantly higher in mothers of children with cerebral palsy (35.17±14.7) than mothers with healthy children (22.05±11.4) (p<0.001). In the caregiver burden sub-scales, the time-dependency burden (TDB) and developmental load (GY) scores were significantly higher in mothers of children with cerebral palsy (p<0.05). Even though the other sub-scales were high in mothers in the CP group, there was no statistically significant difference (Table 4).

Table 4. Comparison of Caregiver Burden scales between groups

	Group 1 Mean ± SD	Group 2 Mean ± SD	P value
CB Total	16.25±7.0	14.5±6.3	p>0.05
	35.17±14.7	22.05±11.4	*p<0.001
Time-Dependency Burden	16.58±4.8	8.72±4.9	*p<0.001
Developmental Burden	7.3±4.2	5.15±3.5	* p = 0.016
Physical Burden	6.21±4.8	5.0±3.6	p>0.05
Social Burden	3.55±3.3	2.41±2.2	p>0.05
Emotional Burden	1.72±1.8	1.02±1.5	p>0.05

CB Caregiver Burden, SD standart deviation

The ratio of patients with CP who had GMFCS scores 1 and 2 was 37.5% and showed functionally good patients. The caregiver burden was significantly lower in mothers with functionally good CP children than those with poor functional status (p=0.019). However, this significance was not observed in HADS scores and anxiety-depression frequencies (p>0.05).

All caregiver burden scale scores were significantly higher in mothers who had children with CP with secondary problems compared to children without any secondary problems (Table 5, p<0.05).

Table 5. The Relationship Between HADS and Caregiver Burden with Secondary Problems

	Secondary Problem (n = 30)	No Secondary Problems (n = 10)	P value
HADS Total score	17.0± 7.3	14.27±6.2	p>0.05
CB Total score	40.25±13.2	21.77±9.3	*p<0.001
Time-Dependency Burden	17.96±3.5	12.93±5.9	* p = 0.02
Developmental Burden	8.62±4.0	3.81±2.4	* p = 0.01
Physical Burden	7.58±4.9	2.61±1.8	* p = 0.02
Social Burden	4.0±3.5	2.36±2.7	p>0.05
Emotional Burden	2.03±1.9	0.90±0.9	p>0.05

HADS Hospital anxiety and depression scale, CB Caregiver Burden

There was no significant difference in HADS scores, caregiver burdens, and anxiety-depression prevalence between children under eight years and older than eight years of age within the CP group (p> 0.05). In the healthy children group, mothers of children under eight years of age had a significantly higher time-dependency burden than the children older than eight years (9.81±4.8 vs. 6.46±4.3 p=0.043).

Discussion

Cerebral palsy is a chronic neurological disorder with movement abnormalities beginning from childhood and monitored in the world and our country. There are many reasons prenatally, natally, and postnatally. Children with cerebral palsy often need care because of their movement disorder and other accompanying problems (mental disorders, epilepsy, eating problems, incontinence, etc.).

CP is classified according to the movement patterns as spastic, dyskinetic, ataxic, and mixed forms. 70-80% of patients are spastic type cerebral palsy [25]. In our study, 85% (n=34) of the children with CP were spastic, 7.5% (n=3) were dyskinetic and 7.5% were mixed type. In this study, we compared the caregiver burden and emotion status of mothers with healthy children and children with cerebral palsy. Mothers, as a result of cultural influences in Turkey, assume responsibility for disabled children and have to devote most of their time only to difficulties caused by the disability. Therefore, we think that mothers' physical and emotional health conditions are impaired. In a study conducted on 486 CP children, 89.7% of caregivers were found to be mothers of children [26]. In our study, caregivers were all mothers of the children. Previous studies have shown that the quality of life and emotional status of mothers who give care to children with CP are worse than mothers with healthy children [27]. However, there is no study comparing the caregiver burden in these two groups. Disability in the child deeply affects the family and the mother, who is especially caring for the child. The physical and psychological health of the family members who have to look after a disabled child during the whole day and years are affected negatively [28,29].

The objective results of caregiving involve the physical changes and preventions in the lives of the caregiver and the family, and are associated with physical problems, such as fatigue due to care, prevention of the family's social and physical routines, physical problems, such as the occurrence or exacerbation of the caregiver's physical illnesses. In many previous studies, it was found that as a result of long-term care, CB can lead to severe depression, anxiety, a decrease in physical health, social isolation, and exhaustion [5,6].

There are many studies [30-32] reporting that mothers of children with cerebral palsy have higher levels of anxiety and depression than mothers with healthy children. Yilmaz et al. found in their study, in which they compared the levels of depression and anxiety in mothers with healthy children and mothers of children, that the levels of depression and anxiety were significantly higher in mothers of children with CP and that they were closely associated with speech disorders and functional status. In our findings, it was found that depression and anxiety levels were significantly higher in mothers of children with CP, who we evaluated with the HADS scale, similar to the previous studies. In our study, we found that the prevalence of depression in the mothers of children with CP (52.5%) was significantly higher than the mothers with healthy children (30%) (p = 0.041). However, no significant difference was found between the groups in terms of frequency of anxiety.

Disabled individuals constitute a significant burden on the family. In 2013, Karahan et al. compared the caregiver burdens in caregivers of 25 cerebral palsy and 25 adult hemiplegic patients and reported a higher burden on caregivers for hemiplegic individuals [33].

Parents, especially mothers of children with CP, may be adversely affected and may have high burden levels [34,35]. This burden of care has been shown to cause a lower quality of life in parents of children with CP [30,36]. In our study, when compared to mothers with healthy children, caregiver burden was significantly higher in mothers of children with CP.

The low functional capacity of the child with cerebral palsy increases the burden on the family. Wijesinghe et al. 375 [37] compared the caregiver burdens of caregiving mothers of children with cerebral palsy and reported that male gender, low functional capacity, and low socioeconomic level increased the caregiver burden. In our study, the caregiver burden, which was evaluated with GMFCS, was found to be significantly higher in mothers of children with lower functional capacity (Stages 3-4-5).

Another important parameter that increases the caregiver burden is that the child is having secondary problems (epilepsy, cognitive problems, speech disorder, vision problem, etc.) except movement disorder. Studies are reporting that mothers of children with CP with cognitive problems have more depression and higher burden than children with CP, who do not have problems [38]. In our study, the caregiver burden of mothers caring for children with CP with additional problems was significantly higher than the children without problems.

The time-dependence burden (TDB), which is one of the sub-parameters of the caregiver burden, was high in both CP and healthy mothers. While TDB was similar among all the mothers of children with CP at all ages, this burden was significantly higher in mothers with healthy children under eight years of age compared to the mothers of healthy children over eight years of age ($p = 0.043$). This finding shows that children with cerebral palsy have a high burden on caregiver's lifelong, but healthy children need less care, especially after school age.

Our study is the first study in the literature comparing the caregiving burden of mothers with healthy children and mothers who give care to children with cerebral palsy. There are a few limitations of our study. The first is the limited number of participants. The second is that since our study is cross-sectional, the effect of the functional improvement in the children with CP on the caregiver's burden and the mother's mood was not measured. Third, the relationship between caregiver burden of the mothers and their quality of life was not evaluated.

Conclusion

Cerebral palsy is a chronic neurological disorder that causes a significant burden of care for the mothers in society and among the societies, especially in patriarchal societies like ours. In our study, both the burden of caregiver and that the frequency of depression was found to be significantly higher than the mothers with healthy children is compatible with this fact. Long follow-up studies are required to examine the changes in quality of life and caregiver burden of mothers of the children with CP and functional recovery in children over time. We think that mothers of children with CP should undergo a regular psychological evaluation and that the mother should be given more psychological and social support.

Competing interests
The authors declare that they have no competing interest.

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Ethical approval
All procedures performed in experiments involving human participants were following the ethical standards of the institutional and national research committee and with the 1964 Declaration of Helsinki.

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