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Stress and depression levels of mothers who give care to children with cerebral palsy and mental retardation: a comparison study

Serebral palsili ve mental retardasyonlu çocuklara bakım veren annelerin stres ve depresyon düzeyleri: karşılaştırmalı bir çalışma

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Abstract

Purpose: Assessment of mothers who give care to children with Cerebral Palsy (CP) and mentally retarded children (MR) by Bakas Caregiving Outcomes Scale and Caregiver Strain Index.

Materials and methods: Fifty-six mothers living in Denizli (children with CP n=33, children with MR n=23) were included the study. Stress of mothers of CP and MR children at the process of giving care, were assessed with Bakas Caregiving Outcomes Scale and Caregiver Strain Index and conditions of depression were assessed with Beck Depression Inventory. Motor development levels of children with CP and MR were determined with Classic Motor Development Level.

Results: When Classic Motor Development Level of children with CP were compared with Bakas Caregiving Outcomes Scale of mothers, a statistically significant and negative correlation was found (p=0.01). In comparison of Bakas Caregiving Outcomes Scale of mothers having children with CP and MR, there was a statistically significant difference towards stress burden of mothers with cerebral palsy children was higher (p=0.03).

Conclusion: We found that caregiving stress of mothers of children with CP was higher. Better motor development level provides less burden of caregiving and depressive symptoms of mothers in disabled children.

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Key words: Cerebral palsy, mentally retarded, stress, depression, caregiving burden

Özet

Amaç: Serebral Palsili (SP) ve Zihinsel Engelli (ZE) çocuklara bakım veren annelerin Bakas Bakım Verme Etki Ölçeği ve Bakım Verenin Stres Ölçeği ile değerlendirilmesi ile bu annelerin stres ve depresyon düzeylerinin karşılaştırılmasıdır.

Gereç ve yöntem: Çalışmaya Denizli'de yaşayan 56 anne (SP'li-n=33, ZE'li-n=23) dâhil edilmiştir. SP'li ve ZE'li çocuk annelerinin bakım verme sürecindeki stresi Bakım Verenin Stres Ölçeği, bakım verme yükü Bakas Bakım Verme Etki Ölçeği ve depresyon durumları ise Beck Depresyon Ölçeği ile değerlendirilmiştir. Çocukların motor gelişim seviyeleri Klasik Motor Gelişim Seviyesi ile belirlenmiştir.

Bulgular: SP'li çocukların Klasik Motor Gelişim Seviyesi ile annelerinin Bakım Verenin Stres Ölçeği puanları karşılaştırıldığında istatistiksel olarak negatif yönlü anlamlı bir ilişki bulunmuştur (p=0.01). SP'li ve ZE'li çocukların annelerinin Bakas Bakım Verme Etki Ölçeği puanları karşılaştırıldığında istatistiksel olarak anlamlı farklılık bulunmuş (p=0.03) ve SP'li çocukların annelerinin stres yükü daha yüksek çıkmıştır.

Sonuç: SP'li çocukların annelerinin bakım verme yükünün daha yüksek olduğunu bulduk. Özürlü çocuk annelerinde daha iyi motor gelişim düzeyi, daha düşük bakım verme yükü ve daha az depresif semptomlar yaratır.

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Anahtar sözcükler: Serebral palsi, mental retardasyon, stres, depresyon, bakım verme yükü

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Introductıon

Cerebral palsy (CP) is defined as the condition that causes movement and postural disorders and restricted movement due to a non-progressive injury in the developing, immature brain. Mental, sensory, conversation, perception, behavior and seizure disorders frequently accompany the motor disorders in CP [1,2]. Being an important disorder that leaves permanent marks on the individual and requires life-long observation, control, care, treatment and rehabilitation, mental insufficiency, similar to other chronic diseases, is a problem that affects all members of the family and the family life in economic, social, emotional, behavioral and cognitive ways [3].

It is known that difficulties in child care and long-term dependency cause strain of the parents [4]. Having a child with CP and mental retardation (MR) increases the stress of the caregivers. The stress of caregiving affects the physiological, psychological, economic and social behavior of the relatives of the patient [5]. Especially the physical and psychological complications of the disease and intense treatment regimens are long-term sources of stress for the patients and caregiving family members [6]. This is why caregiving is a difficult and troublesome process for both the patient and the caregiver [7]. Today, there is no doubt that family needs to be in the caregiving team. Due to the limitations of individuals with chronic disease, the primary caregivers, especially the mother, who is closest to the child, play the most important role in the caregiving process [6]. Finally, the mothers of the children with CP and MR are the primary carriers of the burden and stress of caregiving.

The aim of this study is evaluating the caregiving mothers of children with CP and MR, and the comparison of the stress and depression levels of the mothers of the CP and MR diagnosed children.

Matherial and Method

Participants

Fifty-six mothers (33 with children with CP and 23 with children with MR) who live in Denizli were included in the study. The children with CP and MR were carrying on with their treatments at the special education and rehabilitation centers (Neurodevelopmental Bobath Treatments twice a week and special education once a week).

Informed consents were taken from the mothers and a written permit was taken from the principal of the rehabilitation center (Yagmur Cocuklari special education and Rehabilitation / September 15, 2015) and the ethical principles of the Helsinki Declaration was abided by.

Inclusion criteria

CP and MR diagnosed by a pediatric neurologist

The caregiver of the child has to be child's mother

Exclusion criteria

Any diagnosis other than CP and MR

Children that whose caregiver was not his/her mother

Methods

The demographic data of the children with CP and MR and their mothers who were included in this study was saved. The stress of mothers with children with CP and MR was evaluated with the Caregiver Strain Index (CSI), the change in their lives during the caregiving process was evaluated with Bakas Caregiving Outcomes Scale (BCOS) and their depressive states was evaluated with Beck Depression Inventdry (BDI). The motor development of children with CP and MR was evaluated using the Gross Motor Function Classification System (GMFCS) [8] and the method of Classic Motor Development Level (CMDL) detection.

Caregiver Strain Index

CSI was created by Robinson in 1983 to determine and define the difficulties faced during the caregiving process [9]. The adaptation of the study to the Turkish language was done with Uğur and Fadıloğlu (2010). The scale is made up 13 items. Scores above 7 show the caregiving burden subjectively [10].

Bakas Caregiving Outcomes Scale

BCOS is used to determine the change in the caregivers' lives with the caregiving process [11]. It was created by Bakas in 1994 in accordance with the Lazarus model to determine the changes in the lives of the families with members who have had a stroke [6,11,12]. The adaptation to Turkish, effectiveness and

reliability of the scale was done by Can et al. [6] in 2010. The scale is predictive of both negative and positive values. It is made up 15 questions with scores between +3 (best possible score) and -3 (worst possible score) (-3=1,-2=2, -1=3, 0=4, +1=5, +2=6, +3=7). It is a Likert-type scale that ranges between 1 and 7. The lowest score is 15 and the highest score is 105. The score increases with "positive change" and decreases with "negative change" [6].

Beck Depression Inventory

BDI was created by Beck in 1961 in order to quantitively assess the depressive findings through perception of the participants and its adaptation, effectiveness and reliability study was done in 1988 by Hisli [13]. It has 24 items. Those scoring 17 and above are evaluated as having a risk regarding depressive findings [6,13].

Gross Motor Function Classification System

It is a classification system, which is scored between the levels 1 and 5 that is used for determining functional level compatible with age of individuals with CP. While an individual easily ensures indoor and outdoor ambulation without requiring complimentary mobility devices in the level 1, he/she is completely dependent in terms of mobility in the level 5 [14-17].

Classic Motor Development Level

The level 1 is described that the stage which the child is able to maintain supine or prone position, crawling is defined as level 2 and level 3 is the stage which the child can stand or walk [18].

Statistical Analysis

All statistical analysis were performed using Statistical Package for the Social Sciences (SPSS) v21.0 software. Continuous variables were defined by the mean ± standard deviation and categorical variables were defined by number and percent. Mann–Whitney U test was used for comparing two independent groups. Spearman correlation coefficient was used for correlations between continuous variables. p value ≤0.05 were accepted as statistically significant.

Results

The mean age of the children included in the study with CP was 61.27±36.33 months and those with MR were 106.21±51.12 months. The mean age of the mothers with children with CP was 34.06±6.40 years and that of the mothers with children with MR was 36.04±5.59 years. The socio-demographical data of the mothers and children with CP and MR was shown in Table 1 and Table 2.

Table 1. Demographic characteristics of mothers having children with CP and MR.

	Mothers of Children with CP			Mothers of Children with MR		
	Minimum	**Maximum**	**X ± SD**	**Min.**	**Max.**	**X± SD**
Age (year)	23	47	34.06±6.40	27	46	36.04±5.59
Body Mass Index (kg/cm²)	16.02	35.16	25.64±4.87	19.03	40.58	27.35±6.42
Occupation		**n**	**%**	**n**		**%**
	Housewife	25	75.8	17		73.9
	Worker	2	6.1	3		13.0
	Civil Servant	6	18.2	2		8.7
	Pensioner	-	-	-		-
	Self-Employed	-	-	1		4.3
Educational Level		**n**	**%**	**n**		**%**
	Illiterate	1	3.0	-		-
	Primary School	15	45.5	14		60.9
	Middle School	7	21.2	4		17.4
	High school	5	15.2	3		13.0
	University	5	15.2	2		8.7
Social Security		**n**	**%**	**n**		**%**
	Yes	14	42.4	20		87.0
	No	19	57.6	3		13.0

Table 2. Demographic characteristics of children with CP and MR

	Children with CP			Children with MR		
Age (month)	**Min.**	**Max.**	**X ± SD**	**Min.**	**Max.**	**X ± SD**
	18	132	61.27±36.33	17	215	106.21±51.12
Gender		**n**	**%**	**n**		**%**
	Female	13	39.4	7		30.4
	Male	20	60.6	16		69.6
Cause of CP		**n**	**%**	**n**		**%**
	Prenatal	2	6.1	2		8.7
	Natal	30	90.9	13		56.5
	Postnatal	1	3.0	8		34.8
GMFCS		**n**	**%**	**n**		**%**
	Level 1	2	6.1	-		-
	Level 2	3	9.1	-		-
	Level 3	9	27.3	-		-
	Level 4	4	12.1	-		-
	Level 5	15	45.5	-		-
Motor Development Level		**n**	**%**	**n**		**%**
	Apedal	13	39.4	2		8.7
	Quadripedal	6	18.2	5		21.7
	Bipedal	14	42.4	16		69.6
Clinical Type		**n**	**%**	**n**		**%**
	Spastic	26	78.8	-		-
	Dyskinetic	3	9.1	-		-
	Ataxic	1	3.0	-		-
	Hypotonic	3	9.1	-		-
Extremity Distribution		**n**	**%**	**n**		**%**
	Hemiparesis	7	21.2	-		-
	Diplegia	10	30.2	-		-
	Quadriparesis	15	45.5	-		-
	Monoparesis	1	3.0	-		-

No significant correlation was found to exist between the BCOS and the CSI of the mothers with children who have CP (p=0.30). A statistically highly negative significant correlation exists between the CMDL and GMFCS of the children with CP (p=0.000). There was a statistically significant negative correlation between CMDL of children with CP and their mothers' CSI (p=0.01). Also a statistically significant correlation exists between the GMFCS levels of the children with CP and the CSI of their mothers (p=0.000). A statistically significant correlation was found between the education levels (EL) of the mothers of children with CP and their BCOS (p=0.03). However, the correlation between the BDI and BCOS of the mothers of children with CP was not found to be statistically significant (p=0.15) (Table 3).

A statistically significant negative correlation exists between the BCOS and the CSI of the mothers of children with MR (p=0.000). Upon comparing the BDI and BCOS of the mothers of children with MR, a statistically significant correlation was not found (p=0.08). A statistically significant correlation was found to exist between the CSI and BCOS of mothers of children with MR (p=0.000). A statistically significant correlation was found to exist between the BCOS and the CMDL of children with MR (p=0.000) (Table 4).

When the stress scales of the mothers of children with CP and MR are compared, the stress burden of the mothers of children with CP was found to be significantly higher (p=0.03). In the comparison of BDI of mothers of children with

Table 3. Relationship between the outcome measurements of participants with CP and their mothers

CP	BCOS		CSI		BDI		CMDL		GMFCS		EL	
	R	p	r	p	r	p	r	p	r	p	r	p
BCOS	-	-	-0.18	0.30	-0.25	0.15	-0.20	0.24	0.06	0.72	0.37	0.03*
CSI	-0.18	0.30	-	-	0.10	0.58	-0.44	0.01*	0.51	0.00*	-0.02	0.87
BDI	-0.25	0.15	0.10	0.58	-	-	-0.04	0.80	0.12	0.47	-0.29	0.09
CMDL	-0.20	0.24	-0.44	0.01*	-0.04	0.80	-	-	-0.93	0.00*	-0.07	0.67
GMFCS	0.06	0.72	0.51	0.00*	0.12	0.47	-0.93	0.00*	-	-	0.06	0.73
EL	0.37	0.03*	-0.02	0.87	-0.29	0.09	-0.07	0.67	0.06	0.73	-	-

BCOS: Bakas Caregiver Outcomes Scale
CSI: Caregiver's Stress Index
BDI: Beck Depression Inventory
CMDL: Conventional Motor Development Level
GMFCS: Gross Motor Function Classification System
EL: Educational Levels
* p<0,05 accepted statistically significant

Table 4. Relationship between the outcome measurements of participants with MR and their mothers

MR	BCOS		CSI		BDI		EL	
	r	p	r	p	r	p	R	p
BCOS	-	-	-0.53	0.00*	-0.37	0.08	-0.02	0.90
CSI	-0.53	0.00*	-	-	0.63	0.00*	-0.13	0.55
BDI	-0.37	0.08	0.63	0.00*	-	-	-0.16	0.44
CMDL	0.53	0.00*	-0.36	0.08	-0.30	0.15	0.50	0.01*
EL	-0.02	0.90	-0.13	0.55	-0.16	0.44	-	-

BCOS: Bakas Caregiver Outcomes Scale
CSI: Caregiver's Stress Index
BDI: Beck Depression Inventory
CMDL: Conventional Motor Development Level
GMFCS: Gross Motor Function Classification System
EL: Educational Levels
* p<0.05 accepted statistically significant.

CP and MR, a statistically significant difference was not found (p=0.72). Also, there was no statistically significant difference between the BCOS of the mothers of children with CP and MR (p=0.46) (Table 5).

Discussion

In this study, the mothers of children with CP were found to be significantly more stress-indexed than the mothers of children with MR. This is thought to be due to the fact that CP is

Table 5. Outcome measurements of mothers of children with CP and MR

		Mothers of Children with CP	Mothers of Children with MR
BCOS	**X±SD**	51.63±19.96	55.65±20.46
	p	0.46	
CSI	**X±SD**	7.24±3.70	4.82±4.53
	p	0.03*	
BDI	**X±SD**	15.75±9.84	14.69±12.40
	p	0.72	

BCOS: Bakas Caregiver Outcome Scale
CSI: Caregiver's Stress Index
BDI: Beck Depression Inventory
* p<0.05 accepted statistically significant.

a much more complex situation than MR and is caused by a multitude of other problems that accompany CP.

When the depression levels of the mothers were examined, it was determined that only the mothers of the children with MR had negative effects on the caregiving stress. This is thought to be due to the adverse effects of current mental problems, although there is no gross motor function problem in children with MR.

In the study, it is observed that the care burden of the mothers in both groups is different and this difference is more in the direction of mothers of children with CP. The factor leading to this situation is thought to be the inadequacy of gross motor function in children with CP.

In our study, we found that the stress in the caregiving process is higher in mothers of the children with CP when compared to those of the children with MR. When investigated in terms of the motor development levels of the children with CP and the caregiving stress burden of the mother, it was found that the disability level of the children with CP directly affects the anxiety and stress levels of the mother [2,19]. The dependency of the child with CP increases as does his/her level of disability and it was found that the mother's anxiety and stress levels increase accordingly [20,21].

Based on the data collected from our study, a negative correlation was found between the motor development of the children with CP and the caregiver's strain index. The increase in the motor development levels of the children with CP and MR caused an increase in the BCOS levels of the caregiving mother to increase and the BDI to decrease. When the studies researching the caregiver's strain index of mothers of children with CP are investigated, it is found that the caregiving burden of the mothers increase with the increasing role of the family in taking care of the child [21,22]. In another study, it was seen that the incidence of psychological problems increase in the mothers of children with MR when compared to those of children who do not have MR [23-25].

The results of our study indicate that the better the motor development level of a disabled child, the more positive change and less depressive symptoms in a mother during the caregiving process. The lack of difference in the comparison of the BCOS and BDI of the mothers of children with CP and MR show that the mothers of both groups get similarly affected by the motor development levels of their children.

Limitations of this study were;

- The number of subjects were less
- There were no healthy control group

At the light of these results, we believe that BCOS and CSI can be used to determine how the stress levels and caregiving burdens change in the mothers of children with CP and MR.

Our results in terms of higher stress burden among CP diagnosed children's mothers in comparison to MR diagnosed children's mothers may be related with the higher motor development problems that we see in CP diagnosed children.

Based on our results which are backed up by the literature, considering the role of the family and especially the mother in the rehabilitation team of her child with CP and MR, the negative impact a mother's caregiving burden and stress on the rehabilitation of the child and the importance of the determination of these problems of the mother can be seen more clearly [2,26, 28].

The number of studies done in Turkey on this area -especially in physical therapy- is very small. The literature should be enriched in this regard. This study was conducted to provide information to clinicians and researchers about the burden of care for children with CP and MR.

It should not be forgotten that increasing the level of education and the knowledge of children about problems with mothers who have children with neurological situations, such as children with CP and MR, may positively affect caregiving burdens and depression levels.

All the medical staff from any disciplin who attend the treatment program of these children should take into account while planning the treatment program that these children's quality of life level's decreases but level of depression and burden of caregiving increases.

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