

BURNOUT OF PRIMARY CAREGIVERS OF CHILDREN WITH CEREBRAL PALSY

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ABSTRACT

Objective: The aims of this study were to evaluate the burnout of primary caregivers of children with cerebral palsy (CP), and to assess the relationship between burnout levels and the variables.

Material and Method: Demographic characteristics, CP type, ambulation status, Gross Motor Functional Classification System (GMFCS) levels, accompanying problems were recorded. Caregivers were asked to fill Maslach Burnout Inventory (MBI).

Results: 115 patients were included in the study (56.5% boys, 43.5% girls). Their mean age was 7.84 years. Primary caregivers of 111 children were their mothers (96.5%). The neurologic classification were as follows: diplegia 27.8%, tetraplegia 43.5%, hemiplegia 20%. The GMFCS levels were as follows: level 1 15.7%, level 2 13.9%, level 3 17.4%, level 4 23.5%, level 5 29.6%. MBI subdimensions measurement scores were: reduced personal accomplishment: 23.25, emotional exhaustion: 12.21, and depersonalization: 3.81.

We didn't detect any significant correlation between the GMFCS levels of children and caregivers' burnout. The presence of pain (69.6%) and chronic disease (31.3%) were related with emotional exhaustion ($p=0.006$, $p=0.008$, respectively). The children's ambulation status was related with emotional exhaustion ($p=0.03$). Fathers' lack of interest (27%) was related with depersonalization ($p=0.0019$). Speech disorder was related with emotional exhaustion and depersonalization ($p=0.031$, $p=0.04$, respectively). There was no significant relationship between caregivers' burnout and caregivers' age-education status, income level, the presence of epilepsy and mental retardation in child.

Conclusion: The presence of chronic disease and pain, fathers' lack of interest, children's ambulation status and speech disorders were detected as the factors that cause caregivers burnout. Psychologic and physical health of caregivers affect child. So, not only children with CP but also their caregivers should be considered.

Key Words: Cerebral palsy, caregiver, maslach burnout inventory. *Nobel Med 2011; 7(3): 22-27*

SEREBRAL PALSİLİ ÇOCUKLARA BAKIM VERENLERDE TÜKENMİŞLİK

ÖZET

Amaç: Serebral palsili (SP) çocuklara primer bakım verenlerde tükenmişliği değerlendirmek ve tükenmişlik düzeylerinin değişkenler ile ilişkisini belirlemek.

Materyal ve Metod: Olguların demografik özellikleri, SP tipi, ambulasyon durumu, kaba motor fonksiyonel sınıflama sistemine (KMFSS) göre seviyeleri, eşlik eden ek problemleri kayıt edildi. Bakım verenlere Maslach Tükenmişlik Envanteri (Maslach Burnout Inventory-MBI) dolduruldu.

Bulgular: Çalışmaya alınan 115 SP'li çocuğun %56,5'i erkek, %43,5'i kızdı. Olguların yaş ortalaması 7,84±6,29 yılı. 111 çocuğun primer bakımı ile anneleri ilgileniyordu (%96,5). Nörolojik sınıflamalarına göre olguların %27,8'i dipleji, %43,5'i tetrapleji, %20'si hemiplejiydi. KMFSS'ye göre seviyeleri %15,7'si seviye 1, %13,9'u seviye 2, %17,4'ü seviye 3, %23,5'i seviye 4, %29,6'sı seviye 5'ti. MBI ölçüm puanları ise: duygusal tükenme: 12,21, duyarsızlaşma: 3,81, kişisel başarı noksanlığı: 23,25 olarak saptandı. Çocukla-

rın KMFSS seviyeleri ile bakım verenlerde tükenmişlik arasında anlamlı korelasyon saptanmadı. Bakım verenlerde ağrı varlığı (%69,6) ve kronik hastalık varlığı (%31,3) duygusal tükenmeleri ile ilişkiliydi (sırasıyla p=0,006, p=0,008). Çocukların ambulasyon durumları da duygusal tükenme ile ilişkili bulundu (p=0,03). Babaların çocuklarıyla ilgilenmemesi (%27) duyarsızlaşma ile ilişkiliydi (p=0,0019). Çocuklarda konuşma bozukluğu varlığı da duygusal tükenme ve duyarsızlaşma ile ilişkili bulundu (sırasıyla p=0,031, p=0,04). Bakım verenlerin yaşı, eğitim durumu, gelir düzeyleri, çocuklarda epilepsi ve zeka geriliği varlığı ile bakım verenlerde tükenmişlik arasında anlamlı ilişki saptanmadı.

Sonuç: Serebral palsili çocuklara primer bakım verenlerde kronik hastalık ve ağrılı hastalık varlığı, babanın çocuğa ilgisizliği, çocuğun ambulasyon durumu ve konuşma bozukluğu bakım verenlerde tükenmişliğe yol açan faktörler olarak saptanmıştır. Bakım verenlerin psikolojik ve fiziksel sağlıkları çocuğu etkiler. Dolayısıyla sadece SP'li çocuk değil bakım verenlerini de dikkate almak gerekir.

Anahtar Kelimeler: Serebral palsy, bakım veren, maslach tükenmişlik envanteri. **Nobel Med 2011; 7(3): 22-27**

INTRODUCTION

Cerebral palsy (CP) describes a group of disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain.¹ Although CP is the most common cause of motor deficiency in young children, it occurs in only 2 to 3 per 1000 live births.²⁻⁴ The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, cognition, communication, perception, and/or behaviour, and/or by a seizure disorder.¹

Because of the accompanying problems, children with CP need a caregiver for their activity of daily living (ADL). Parents are the natural caregivers. Having a handicapped child, being a caregiver for a long time, absence of the other family members' support can cause burnout of caregivers. Burnout is a psychological syndrome of emotional exhaustion, depersonalization, and reduced personal accomplishment that can occur among individuals who work with other people in some capacity. Maslach Burnout Inventory (MBI) is a standardised objective measurement device to assess burnout and was developed by Maslach and Jackson. MBI contains three subscales that assess the different

aspects of experienced burnout. It has been found to be reliable and valid.⁵ Pelsma and friends examined the validity of MBI for assessing parental burnout.⁶ It has been adapted and translated by Ergin into Turkish, and shown to be reliable and valid. Ergin used MBI to assess the burnout of doctors' and nurses.⁷ Duygun and Sezgin also were the first who used MBI in handicapped children's caregivers in Turkey. They changed the instructions of the questionnaire into "my child" instead of "my recipients" and "the care of my child" instead of "my work" or "my job".⁸

The close contact with the disabled person and deep interpersonal contact is common and this closeness may result in emotional exhaustion as well as in burnout.⁹ So burnout can lead to deterioration in the quality of care.⁵ Another proposed outcome of burnout is the impairment of one's relationships with people in general.⁵

The aim of this study was to evaluate the burnout of primary caregivers of children with CP, and to assess the relation of burnout levels with the variables.

MATERIAL and METHOD

The participants were selected from Göztepe Education and Research Hospital Physical Medicine and →

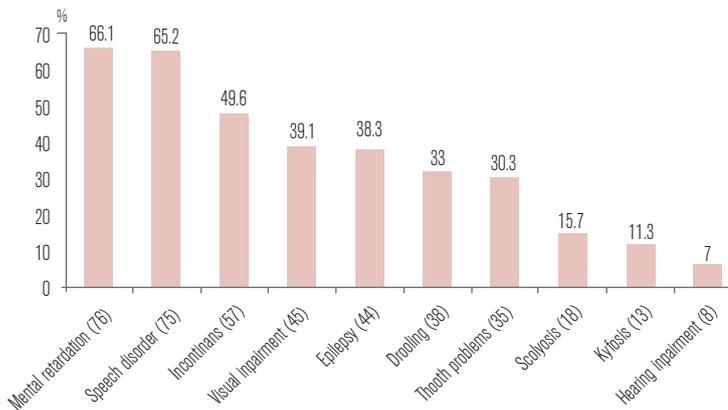


Figure. Accompanying disorders of the children

Table 1: MBI subdimensions measurements scores					
	n	Minimum	Maximum	Mean	Std. Deviation
Emotional exhaustion	115	0	30	12.21	5.77
Reduced personal accomplishment	115	13	32	23.25	4.85
Depersonalization	115	0	27	3.81	4.05

Table 2: The relation between the MBI subdimensions measurements scores and father's lack of interest to the child					
Father's lack of interest	No (n=31)	Yes (n=83)	t	p	
Emotional exhaustion	13.68±5.96	11.65±5.67	1.68	0.097	
Reduced personal accomplishment	22.81±5.13	23.42±4.8	-0.60	0.551	
Depersonalization	5.26±5.45	3.27±3.3	2.37	0.019	

Table 3: The relation between the MBI subdimensions measurements scores and presence of pain					
Presence of pain	No (n=35)	Yes (n=80)	t	p	
Emotional exhaustion	10±5.37	13.18±5.7	-2.795	0.006	
Reduced personal accomplishment	23.74±5.54	23.04±4.54	0.716	0.476	
Depersonalization	2.86±3.12	4.22±4.35	-1.679	0.096	

Rehabilitation Clinic, and special education centers. The parents were met in the special education centers while their children were having special education or group therapy. Ethical approval for the study was obtained from the ethical committee of the hospital. The parents were informed about the aim of the research and their written informed consent was taken. The general questionnaire included questions regarding age, gender, education level, occupation, number of children, health insurance, socio-economic levels. They were also asked about the presence of another person who look up the child whole day when needed, presence of another person at home who need care (grandmother, grandfather, another handicapped child) and fathers' lack of interest to the child, if they had pain and chronic diseases. Children's

demographic characteristics (included age, education level, accompanying problems), CP type, ambulation status, Gross Motor Functional Classification System level were recorded by the researchers.

The functional level has been determined based on the Gross Motor Function Classification System (GMFCS). GMFCS which is a classification system specifically devised for children with CP, is classified into 5 levels according to gross motor movements. For each level, separate descriptions are provided. Level I is the mildest. Children in level III usually require orthoses and assisting mobility devices, while children in level II do not require assisting mobility devices after age 4. Children in level III sit independently, have independent floor mobility, and walk with assisting mobility devices. In level IV, affected children function in supported sitting but independent mobility is very limited. Children in level V lack independence even in basic antigravity postural control and need power mobility.¹⁰

At the beginning of the meeting, oral instructions were given to the parents by the researcher. The socio-demographic form and MBI were completed by themselves. Total time for completing the questionnaire was approximately 30-45 minutes. The data were collected in June 2007 by the researcher. MBI is the most frequently used scale for measuring burnout. The MBI consists of 22 items and it describes burnout as a three-dimensional syndrome characterized by emotional exhaustion (9 items), depersonalization (5 items) and reduced personal accomplishment (8 items).

The respondents answer the statements about personal feelings or attitudes in terms of how frequently they experienced the stated situation on a 7-point scale. It is adapted and translated into Turkish by Ergin and the 7-point scale was converted into a 5-point scale (0=never; 4=always).⁷

The nine items in the Emotional Exhaustion subscale assess feelings of being emotionally overextended and exhausted by one's work. The five items in the Depersonalization subscale measure an unfeeling and impersonal response toward recipients of one's service, care, treatment or instruction. For both the Emotional Exhaustion and Depersonalization subscales, higher mean scores correspond to higher degrees of experienced burnout. The eight items in the Personal Accomplishment subscale assess feelings of competence and successful achievement in one's work with people. In contrast to the other two subscales, lower mean scores on this subscale correspond to higher degrees of experienced burnout.⁵ →

Statistical analyses

In this study the statistical analyses were performed with the GraphPad Prisma V.3 packet program. Descriptive statistical methods (mean, standart deviation) were used for assesing data. The comparisons of parameters were performed with one way ANOVA test, and independent t-test. Spearman's rank correlation was used for the correlation between the variables and X² test was used to compare qualitative data. A *p* value of ≤0.05 was considered statistically significant.

RESULTS

115 patients were included in the study (56.5% boys, 43.5% girls). Primary caregivers of 111 children were their mothers (96.5%). The other four were grand mother, aunt and oldest sister. Their mean age was 34.46±9.41 years. The mean number of siblings was 2.15±1.09. Most of the mothers were housewives (93.6%). Only 0.9% of the fathers were unemployed. Most of the mothers graduated from elementary school (55.7%). Also nearly half of the fathers were graduated from elementary school (43.9%). Only 1.7% of the families hadn't got a health insurance. 26.1% of the children could be looked up by another person when needed; they were generally the grand mothers, aunts and sisters. Only 10.4% of the caregivers were also a caregiver for another person at home. 27% of the mothers were complaining about the fathers' lack of interest to their child. 69.6% of the caregivers had pain and 31.3% had chronic diseases.

The children's mean age was 7.84±6.29 years. 87% of them were illiterate. The distribution of cerebral palsy types was as follows: diplegia 27.8% , tetraplegia 43.5%, hemiplegia 20%. Cerebral palsy severity as assessed by the GMFCS level was distributed as follows: level 1, 15.7%; level 2, 13.9%; level 3, 17.4%; level 4, 23.5%; level 5, 29.6%. 23.5% of the children were ambulant, 53.9% were nonambulant, 21.9% were using assistive devices for ambulation. Figure shows accompanying disorders of the children.

Table 1 shows the MBI subdimensions measurements mean scores. The relation of burnout levels with the variables were assessed. Father's lack of interest to the child, presence of pain, presence of chronic disease, ambulation status of the child, speech disorder of the child were the variables which we found significantly associated with burnout subdimensions (Table 2-6 respectively).

There was no significant relationship between caregivers' burnout and caregivers' age, education status, the presence of another caregiver for the child,

Table 4: The relation between the MBI subdimensions measurements scores and presence of chronic disease

Presence of chronic disease	No (n:79)	Yes (n:36)	t	p
Emotional exhaustion	11.25±5.48	14.31±5.92	-2.70	0.008
Reduced personal accomplishment	23.08±4.66	23.64±5.31	-0.58	0.566
Depersonalization	3.68±4.25	4.08±3.63	-0.49	0.626

Table 5: The relation between the MBI subdimensions measurements scores and child's ambulation status

Ambulation status	Ambulant (n:27)	Non Ambulant (n:62)	Assistive Ambulant (n:25)	F	p
Emotional exhaustion	12.19±6.41	13.26±5.78*	9.64±4.35*	3.63	0.03
Reduced personal accomplishment	23.48±5.1	22.94±4.82	23.8±4.89	0.32	0.731
Depersonalization	3.48±3.06	4.37±4.82	2.52±2.16	2.00	0.141

Table 6: The relation between the MBI subdimensions measurements scores and child's speec impairment

Speech impairment	No (n:40)	Yes (n:75)	T	p
Emotional exhaustion	10.63±4.95	13.05±6.02	-2.19	0.031
Reduced personal accomplishment	23.38±4.94	23.19±4.84	0.20	0.844
Depersonalization	2.75±2.24	4.37±4.66	-2.08	0.04

the presence of another person at home who need care, the presence of epilepsy and mental retardation (MR) in child. We didn't detect any significant correlation between the caregivers' burnout and GMFCS levels and CP type of the children.

DISCUSSION

MBI has been designed for measuring occupational burnout in people-oriented professions.⁵ Burnout syndrome was also evaluated among caregivers, such as family caregivers of people with demented elderly,⁹ psychiatric patients,¹¹ multiple sclerosis and cancer patients.¹² Caregivers experiencing burnout were also found to have limitation in social life, poor health, lack of positive outlook on caring.⁹ So caregiving is stressful for the caregiver.

In a study, family caregivers of cancer and multiple sclerosis patients burnout were assessed and found higher to the extent that their ill partners experienced more symptoms of depression.¹² Almgberg reported that caregivers of demented elderly experienced burnout.⁹ Also burnout was evaluated among the partners of mentally ill people and the nursing staff working in psychiatric facilities. Both groups showed similarly high scores in all three dimensions of burnout.¹³ Although caregiver burnout was assessed in different studies there are few studies about parental burnout.^{6,8}→

As far as we know, this is the first study to evaluate the burnout of caregivers' of CP. Cerebral palsy is the third most common major developmental disability, after autism and mental retardation.¹⁴ CP is often associated with epilepsy and abnormalities of speech, vision, intellect.^{3,14} Because of the accompanying problems, children with CP need a caregiver for their activity of daily living.

While caregiving is a normal part of being the parent of any young child, providing the high level care required by a child with long-term functional limitations can become burdensome and may impact upon both the physical and mental health of the caregiver. In addition, families of disabled children have to cope with greater financial stress, more frequent disruption of family routine and reduced social activities outside the family.¹⁵ In our study, nearly all of the mothers were housewives (93.6%). Due to being at home most of the time, they may be more involved with the caring of the child.

Although speech disorder of the child was significantly associated with burnout subdimensions, there were no significant relationship between caregivers' burnout and child's mental retardation. However it was detected that burnout mean scores of the mothers with mentally handicapped children were higher than the mean scores of the mothers of healthy children.⁸

Child behavior problems were found the single most important child characteristic that predicts caregiver psychological well-being. Also it was reported that the psychological and physical health of caregivers, who were primarily mothers, was strongly influenced by caregiving demands and family function.¹⁶ It was demonstrated that a high proportion of mothers of children with CP suffer from behavior problems in children, especially those related to burden of caring. Child's lack of independence in daily living skills was found the most significantly associated problem with maternal stress.¹⁷

No significant correlation was detected between the caregivers' burnout and GMFCS levels and

CP type of the children in our study. Ones et al. reported depression and lower quality of life in the mothers of children with CP, but they also found no correlation between GMFCS levels of children neither with depression nor with quality of life of mothers.¹⁸ However the severity of a child's motor disability was found to be associated with a decrease in the physical and psychological well-being of the mother.¹⁵ In another study, level of child impairment and developmental status were detected as significant independent predictors of maternal stress.¹⁹

In our study, presence of pain and chronic disease were related with emotional exhaustion. In another study, primary caregivers of children with CP scored higher in distress and in chronicity of distress than the control group. It was found that caring for a child with a disability is associated with poorer psychological and physical health of the caregiver. The burden of caregiving increases stress level, which then manifests itself in a variety of chronic conditions.²⁰

In conclusion, the mother, as a primary caregiver, is the centre of support for the needs of the child with CP. If the mother's psychological and physical health is not well than the child suffers. The burnout syndrome can cause symptoms that can negatively affect the quality of life of the caregiver. This syndrome may be also associated with stress related health problems. The daily demands of home care may gradually exhaust families. Burnout is no longer healthy for both the caregiver and the child. So, educating the parents about their possible stress resource and showing the ways to solve the problems would help them to experience less stress. These can help to reduce their burnout.

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