

# Burnout of Formal Caregivers of Children with Cerebral Palsy

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## ABSTRACT

**Background:** Burnout syndrome is under-researched within caregivers (CGs) of children with cerebral palsy. The primary aim was to determine the burnout level of formal CGs of children with cerebral palsy (G1) and to compare it with a control group (G2) of professional pediatric nurses, and second, to correlate the level of depression and anxiety with the burnout level.

**Method:** In a total sample of 60 CGs, the Maslach Burnout Inventory Human Services Survey (MBI-HSS), consisting of three structural units - emotional exhaustion (MBI-EE) subscale, depersonalization (MBI-DP) subscale and personal accomplishment (MBI-PA) subscale - was used to measure burnout. The Beck Anxiety Inventory (BAI) was used for the assessment of anxiety, and the Beck Depression Inventory (BDI) for depression.

**Results:** A significant difference was shown on the MBI-EE subscale and on the BDI test ( $p < 0.05$ ), in both cases higher scores were obtained by G1. High burnout was observed in all subscales, on the MBI-EE subscale registered 50% of CGs in G1, and 17% in control G2. Correlation of the MBI-EE subscale with BDI and BAI tests was highly significant ( $p < 0.01$ ).

**Conclusions:** These findings indicate the need for future research aimed at formulating preventive strategies for caregivers' mental health. Better care for caregivers would provide them with better professional satisfaction, and consequently would lead to better care for patients.

## INTRODUCTION

Investigation of caregivers' (CGs) burnout is important for many reasons, including the risk of low perceived work ability, malpractice in caregiving, intention to leave nursing and problems with absenteeism (1, 2). In general, literature emphasizes the role of caregivers' interaction with patients' disability and their challenging behavior in caregiver burnout (3, 4). For example, professional caregivers of geriatric patients are at risk of burnout because working with the elderly means a continuous confrontation with serious illness and death (5), while the responsibilities of a psychiatric CG (nurse) are defined largely by very specific treatment guidelines and daily routines (6).

Burnout in relatives, i.e., informal CGs, originates from personal closeness to the patient (7). In the case of nursing staff and other formal CGs, it stems from their own emotions, and from unpredictable, specific situations in their work, as well as from their work organization (8). Formal care is often characterized by the numerous demands and arduous tasks that have to be done (9). Following a review of important studies, Barling (10) concluded that mental health nurses suffer a high degree of burnout. Although they may be more prone to burnout than other nursing groups, pediatric nurses represent a relatively under-researched group (11).

While previous research of burnout in the geriatric and psychiatric domain was orientated more toward professional caregivers, in the relevant literature about caregiving of children with cerebral palsy we find the opposite situation - there are many studies focused on burnout of primary CGs, mostly mothers (12-14). Care of ill children involves specific burdens, and becomes more significant

if the child has a developmental or physical disability. Intense and long care for these children can have different effects on the mental (and physical) health of the caregiver. Cerebral palsy, a complex developmental disorder, might require specific caregiving extending into the adult period. The main characteristic of cerebral palsy (CP) is impaired motor function, and this might be worsened by sensory and intellectual impairments and limitations in self-feeding, grooming and mobility (15). The effects of caring for children with CP on their caregivers, and a negative impact on their mental health, have been reported by Mobarak et al. (16) and Raina et al. (17). Although there are studies investigating burnout of mothers and relatives, as primary and informal CGs of children with CP, scarce information, however, exists on the mental health of the formal caregivers of children with CP. Furthermore, to our knowledge, there is no published paper regarding the burnout issue in this specific population of professional CGs. Therefore, our primary aim was to determine the burnout level of formal CGs of children with cerebral palsy, due to the complexity of their specific job, and to compare them with a control group of professional pediatric nurses who are CGs of normally developing, non-CP children.

Furthermore, caregivers are generally at risk of negative mental and physical health outcomes, such as depression, anxiety and high blood pressure (18-20), which might also impact their quality of life (QOL) (21). High levels of psychological distress, exhaustion, stress, anxiety, depression, and hopelessness in caregivers of people with dementia were found in a recent study in Brazil (22). Depression and anxiety are frequently seen in caregivers of people with Alzheimer's disease, with a depression prevalence ranging from 30% to 55% (23, 24). There is little information in the literature correlating CGs' burnout to anxious and depressive symptoms, while a higher burnout score could implicate higher levels of depression and anxiety. Therefore our secondary aim was to examine the level of depression and anxiety in both CG groups, and its correlation with burnout level.

## METHODS

### SAMPLE AND PROCEDURE

The participants in this case control study were 60 formal CGs in a total sample, with the main group consisting of 30 formal CGs of children with CP, i.e., nurses/technicians at the Special Hospital for Cerebral Palsy and Developmental Neurology in Belgrade, while the control group was comprised of 30 pediatric nurses/technicians, as caregivers of

normally developing, non-palsy children in the Department of Pulmonology and Allergology of the University Children's Hospital in Belgrade. Both institutions are secondary health care institutions, with a similarly high level of service delivery, and both are part of the public health care system. It is important to emphasize that despite the relatively small sample size, the main group in practice represents the total number of available professional caregivers of children with CP in Serbia. All the children with CP in the actual sample belonged to the classification group referred to as "more independent" children (hemiplegic and diplegic - and according to the Gross Motor Function Classification System GMFCS [25], levels I and II), meaning children with a lower level of physical and intellectual disabilities of CP, also with minimum compromised level of communication. The overall response rate was excellent (97%). The criteria for inclusion were 40 working hours per week and work in hospital units, as well as caregiving of children aged 1 to 12 years. Precise data on the amount of physical work was not available, except the fact that CGs in both groups had the same number of working hours. Exclusion criteria included the presence of severe mental illness and work in the out-patient department. Regarding variables of income and educational level, all participants were in the same salary and education category, so these variables were not included in the analysis. The ethical committees of the above mentioned institutions approved this study. Researchers personally asked participants to participate and explained the details of the study. All the participants gave their informed consent and were able to reply anonymously.

### INSTRUMENTS

The socio-demographic questionnaire contains basic personal data on age, gender and years of experience.

The Maslach Burnout Inventory (MBI) (26) has three structural units and 22 items; we used the MBI-HSS version (Human Services Survey) (27) prescribed for medical workers, that measures the following: (1) the emotional exhaustion (MBI-EE) scale assesses feelings of being emotionally overburdened and exhausted by one's work; (2) the depersonalization (MBI-DP) scale assesses the presence of an unfeeling and impersonal response towards the recipients of one's efforts; (3) the personal accomplishment (MBI-PA) scale assesses feelings of competence and successful achievement related to one's work. Each subscale score can be categorized as low, average or high burnout as defined by the normative data.

The Beck Anxiety Inventory (BAI) (28) was used for quantitative assessment of anxiety. BAI was primarily

designed to measure general anxiety and distinguish the symptoms of anxiety from those of depression. It consists of 21 items, and the questions are ranked on a scale from 0 - 3 (0 = none, 1 = mild, 2 = moderate, 3 = severe). The maximum score is 63. Scores 0-7 correspond to minimal anxiety, 8-15 to mild, 16-25 to moderate, and 26-63 to severe anxiety. Qualitative analysis of anxiety was related to determining presence/absence of some anxiety symptoms, based on the list of comprehensive anxiety symptoms.

For assessment of depression a Beck Depression Inventory (BDI) was used (29). BDI is a 21-item self-rating scale that covers different depressive symptoms, e.g., feelings of sadness, concerns about the future, suicidal ideation, tearfulness, sleep, fatigue, interests, worries about health, sexual interest, appetite, weight loss, and general enjoyment. Each item is rated 0, 1, 2 and 3 denoting increasing severity of symptoms.

Cronbach's alpha values of internal consistency (30) obtained for all the scales, indicated good reliability (MBI-EE  $\alpha = 0.86$ , MBI-DP  $\alpha = 0.78$ , MBI-PA  $\alpha = 0.75$ , BDI  $\alpha = 0.81$ , BAI  $\alpha = 0.76$ ).

**STATISTICAL ANALYSIS**

The SPSS version 17.0 package was used for statistical analysis. Description of numerical characteristics was done by using classical methods of descriptive statistics (mean, standard deviation, standard error). The  $\chi^2$ -test was used to compare the difference between frequencies of nonparametric characteristics, for one or two variables. For the comparison of mean values of parametric features we used the t-test for two groups of data. In the connectivity analysis methods of single and multiple correlation were applied. In all the analytical methods used the level of significance was 0.05.

**RESULTS**

The study was based on 60 caregivers (GGs), the main group (G1) consisted of 30 formal CGs of children with CP, while the control group (G2) was comprised of 30 pediatric nurses/technicians. The age difference between groups (G1mean=39.43/G2 mean=39.97) was not significant ( $p > 0.05$ ), as well as the statistical difference by gender ( $\chi^2=1.071$ ,  $p=0.301$ ), while female CGs dominated, G1-90% and G2-97%. Between average years of experience in CGs groups (G1-mean=9.97, G2-mean=15.93), the difference was statistically significant ( $t = -2.746$ ,  $p < 0.01$ )

Analysis of the total score of MBI test subscales, as well BAI and BDI tests between groups, showed a statistically

significant difference on the MBI-EE subscale ( $t=2.445$ ,  $p=0.018$ ), and on the BDI test ( $t=2.236$ ,  $p=0.029$ ), in both cases CGs of the main group had higher scores. Regarding the BAI test, total values were slightly higher in the CGs of children with CP, but without significant difference (Table 1).

In Table 2 the level of burnout risk in both groups is shown. High burnout risk was registered by all three subscales, on the MBI-EE subscale 50 % of CGs in G1 and 17% in G2 registered as being in this category. The subscale MBI-DP reported only low and high burnout risk, as well

**Table 1.** Relation of burnout, anxiety and depression between caregivers' groups

Group	N	Mean	SD	t	p	
MBI-EE	G1	30	25.67	15.043	2.445	0.018
	G2	30	17.57	10.153		
MBI-DP	G1	30	4.13	5.594	-0.252	0.802
	G2	30	4.47	4.584		
MBI-PA	G1	30	36.40	6.473	0.014	0.989
	G2	30	36.37	11.180		
BAI	G1	30	12.50	12.594	0.199	0.843
	G2	30	11.97	7.577		
BDI	G1	30	8.53	9.108	2.236	0.029
	G2	30	4.43	4.232		

**Table 2.** Level of burnout risk in both CGs' groups

		CGs' group					
		G1		G2		Total	
		N	%	N	%	N	%
MBI-EE	Low burnout risk	10	33	16	53	26	43
	Medium burnout risk	5	17	9	30	14	24
	High burnout risk	15	50	5	17	20	33
	Total	30	100%	30	100%	60	100%
MBI-DP	Low burnout risk	26	87	25	83	51	85
	High burnout risk	4	13	5	17	9	15
	Total	30	100%	30	100%	60	100%
MBI-PA	Low burnout risk	9	30	14	47	23	38
	Medium burnout risk	12	40	9	30	21	35
	High burnout risk	9	30	7	23	16	27
	Total	30	100%	30	100%	60	100%

Pearson's $\chi^2$ test			
	CGs' group		
	$\chi^2$	df	p
MBI-EE	7.527	2	0.023*
MBI-DP	0.131	1	0.718
MBI-PA	1.766	2	0.414

as a notably low percent in high burnout category (G1-13% vs. G2-17%), while distribution on MBI-PA (high burnout in G1-30% vs. G2-23%) was similar to the MBI-EE subscale. A statistically significant difference between G1 and G2 groups, regarding the percent of burnout risk, was obtained only by MBI-EE subscale ( $\chi^2=7.527$ ,  $p=0.023$ )

Analysis of the correlation of the MBI-EE subscale with BDI and BAI tests, separately for each CGs' group, was highly statistically significant (G1 - MBI-EE/BDI:  $r = 0.642$ ,  $p < 0.01$ ; G1 - MBI-EE/BAI:  $r=0.541$ ,  $p < 0.01$ ; G2 - MBI-EE/BDI:  $r=0.707$ ,  $p < 0.01$ ), which means that a higher score on the MBI-EE coincides with a higher score of the BDI and BAI (Graph 1). The only exception was the relation between the MBI-EE and the BAI test in G2, where no significant correlation ( $r=0.340$ ,  $p > 0.05$ ) was found.

The division of each CGs' group into two categories, the less (1-10 years of experience) and more (11 and more years) experienced, and comparison with MBI-EE scores showed higher burnout scores in the more experienced category in G1 (MBI-EE mean- 21.56/30.36), as well in G2 (MBI-EE mean- 14.73/19.21) group. The division of the already small sample did not result in a statistically significant difference but was nevertheless noticeable, as seen above ( $t_1 = -1.644$ ,  $p_1=0.111$ ;  $t_2 = -1.173$ ,  $p_2=0.251$ ).

## DISCUSSION

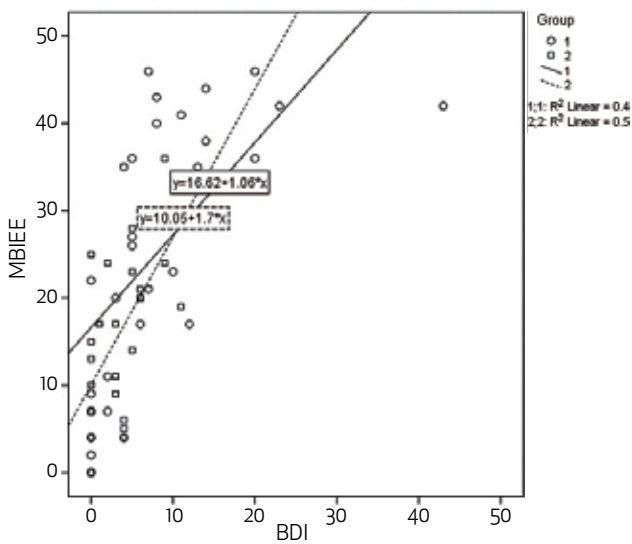
In this study, the level of burnout and its relationship with anxiety and depression symptoms within a group of professional CGs, i.e., the main group (G1) of formal

CGs of children with CP and the control group (G2) of 30 pediatric nurses/technicians, was explored.

Analysis of the total score of MBI test subscales between groups showed a statistically significant difference on the MBI-EE subscale, and CGs of CP children, i.e., G1 group, had higher scores. This finding is important because it concerns our primary aim. Regarding mean values on MBI-DP and MBI-PA subscales, there was almost no difference. Although many studies of CGs' burnout ascribe the largest influence and importance to the emotional exhaustion subscale - MBI-EE (31, 32), its interpretation is also related to the other two subscales of MBI (33). Similar findings on MBI-DP and MBI-PA between G1 and G2 could suggest, with caution, that caregivers in the control group could also suffer a high degree of burnout, and therefore it would not be possible to establish a more significant intergroup difference. The data in Table 2 give us more information, representing the precise percentage of the level of burnout risk. In G1 50% reported high burnout risk on EE, versus 17% in G2, and again with a statistically significant difference. These results justify and better explain the above mentioned statements. A comparison with other studies is difficult, as mentioned in the Introduction, because there are few studies analyzing burnout of caregivers of cerebral palsy children, and in all of them the sample consisted of informal, primary caregivers (12-14). However, there is a wide body of relevant literature dealing with burnout of other CGs in the health system, and most report high levels, especially for MBI-EE, which vary in range from 10% (34), 17.4% (5), to 53% (35), with the majority about 30% (36, 37). In this regard, our result in G1 (50%) indicates a very high and alarming degree of burnout. Furthermore, a low burnout risk obtained on MBI-DP subscales in both groups is consistent with the available literature where many investigations showed, we could say generally, a low level obtained on this scale (38, 39).

Regarding the BAI test, total values were slightly higher in the CGs of children with CP, but without significant difference (Table 1), and mean values in both groups belong to the category of "mild anxiety," according to the test score key. Furthermore, in the BDI test, CGs of the main group had significantly higher scores, which is consistent with the finding on the MBI-EE subscale. However, it is notable that BDI mean values in G1 and G2 are in the category "without mood disturbance," which could indicate an absence of serious depressive pathology, when analyzing average scores. Looking more closely, we find higher than average values, 30% in G1 had clinical depression symptoms (BDI), while about 50% CGs in each group had some form

**Graph 1.** Correlation of MBI-EE and BDI score in both CGs' groups





of clinical anxiety (BAI), nevertheless indicating a presence of depression and anxiety pathology. These results are similar to other studies, some report 43% cases of anxiety (34), others 53% of anxiety and 17% of depression (40).

Regarding each group separately, among all burnout dimensions, emotional exhaustion was highly correlated to anxiety and depression variables ( $p < 0.01$ ), the only exception being the relation between the MBI-EE and BAI tests in the control group, where no significant correlation was found ( $p > 0.05$ ). The participants whose results showed higher burnout had higher scores measured by the BAI and the BDI tests, which was relatively expected, and this represents a response to the second aim of this study. Huggard notes that in order to care for the carers, health care organizations need to “develop respect and care for their employees in the same way that they require their employees to care for their patients” (41), while Kumar et al. propose that “organizational leaders must work with their staff to develop a workplace environment...” (42). In the similar context, a correlation of burnout and depression, as well as anxiety, found in this study, could potentially contribute to the future development of preventive strategies in this field in Serbia.

The division of each CGs' group into two categories, the less (1-10 years of experience) and more (11 and more years) experienced, and comparison with MBI-EE scores, showed higher burnout scores in the more experienced category in G1, as well in G2 group, but no statistical difference was observed due to the division of an already small sample into even smaller parts. However, finding higher burnout scores among the more experienced CGs in G1 (MBI-EE mean = 21.56/30.36), as well as in G2 (MBI-EE mean = 14.73/19.21) group, is in line with a published Lithuanian study (43), while Morita et al. (44) reported the opposite, that the less experienced CGs had higher burnout.

As mentioned before, this is, to our knowledge, the first study in academic literature examining burnout of formal, professional caregivers of children with cerebral palsy, while there are only a few studies investigating the area of informal caregivers, such as relatives. This fact indicates the potentially major contribution of this study.

However, certain limitations of this study should be noted. An important limitation is the relatively small sample size, but in view of the fact that Serbia is a small country and cerebral palsy is a rare disorder, with an incidence of 2.0 to 2.5 per 1,000 live births in developed countries (45), the sample is acceptable for a study examining this specific issue. Caution should be taken, however, in

interpreting these results to avoid overgeneralization. Regarding the sample size in this research field, we find articles in reputable journals with samples ranging from 37 to 60 participants (46-48). Furthermore, this study did not investigate personal factors and characteristics of CGs, or their coping strategies, which could better explain the burnout level and give us more valuable correlations (49). Our findings only reflect the situation in Serbia, which could be seen as both a contribution and a limitation. When planning this research, we decided not to include an investigation about the level of motor disability of children with CP because many studies clearly showed there is no significant relation between the severity of CP symptoms and caregivers' mental health (12, 13, 50). Furthermore, although the general question of employment patterns and recruitment in the care taking field undoubtedly deserves a separate analysis, due to the design limitations of this study we were able to investigate only the years of experience relevant to the topic, and to include the criterion that all participants had five or more years working experience in the health care system. In this regard, this study's findings could also contribute to improving the recruitment system and imply strict selection criteria in the employment of caregivers. According to the limitations mentioned, there are plans for a larger, multicentric study which would include samples of CGs from surrounding countries, with similar health care systems. However, it would be preferable to conduct a follow-up design, instead of a cross-sectional one, due to its limitations in interpreting results. It would also be beneficial to consider and better explore working conditions and organizational factors in this field, which certainly influence burnout and the mental health of employees. Similarly, to our knowledge, staff support systems in the caregiving field deserve detailed analysis and improvement, and require supervising and educational support programs for employees. Currently, available data suggest that the employees' only benefit is a slightly higher number of vacation days. In order to improve the caregivers' service and to provide additional implications to non-professional CGs, mainly parents, future research should include examination of the type of contact the CGs have with the families, because better communication with parents means greater benefit for both sides in a demanding therapeutic process. The findings of this study related to the level of anxiety and depression in professional CGs also require caution and imply preventive measures when it comes to the mental status of parents as informal CGs.

## CONCLUSION

To summarize, the current study found higher burnout scores among caregivers of children with cerebral palsy than in the control group, although high burnout levels there were observed too, and when taking into consideration the total sample, the participants whose results showed higher burnout had more prominent anxiety and depression symptoms, measured by the BAI and the BDI tests. These findings suggest the need for future research in order to verify the importance of this causality, as well as to examine in detail the influence of many possible factors related to caregivers' burnout, such as personal psychological aspects of CGs and work environment and organizational factors. Furthermore, formulation of preventive psychotherapeutic strategies and interventions at the national level in all caregivers' sectors is recommended. Better care of caregivers' mental health would provide them with better personal and professional satisfaction, and would consequently lead to a higher level of patient care.

## Conflict of interest

The authors declare that there is no conflict of interest. They have not benefited from any sponsorship or funding.

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