

# Management of Informal Caregivers' Burden in a Selected Region of the Czech Republic

H. Zaskodna (Helena Zaskodna)<sup>1</sup>, S. Bartlova (Sylva Bartlova)<sup>2</sup>, O. Dvorackova (Olga Dvorackova)<sup>3</sup>, H. Hajduchova (Hana Hajduchova)<sup>2</sup>, L. Motlova (Lenka Motlova)<sup>4</sup>, M. Treslova (Marie Treslova)<sup>2</sup>, I. Baloun (Ingrid Baloun)<sup>4</sup>, T. Hrdy (Tomas Hrdy)<sup>5</sup>, V. Staskova (Vera Staskova)<sup>2</sup>, I. Brabcova (Iva Brabcova)<sup>2</sup>

Original Article

<sup>1</sup> Institute of Humanities in Helping Professions, Faculty of Health and Social Sciences,

University of South Bohemia in Ceske Budejovice, Ceske Budejovice, Czech Republic.

<sup>2</sup> Institute of Nursing, Midwifery and Emergency Care, Faculty of Health and Social Sciences, University of South Bohemia in Ceske Budejovice, Ceske Budejovice, Czech Republic.

<sup>3</sup> Institute of Laboratory Diagnostics and Public Health, Faculty of Health and Social Sciences, University of South Bohemia in Ceske Budejovice, Ceske Budejovice, Czech Republic.

<sup>4</sup> Institute of Social and Special-paedagogical Sciences, Faculty of Health and Social Sciences, University of South Bohemia in Ceske Budejovice, Ceske Budejovice, Czech Republic.

<sup>5</sup> Institute of Physiotherapy and Selected Medical Disciplines, Faculty of Health and Social Sciences,

University of South Bohemia in Ceske Budejovice, Ceske Budejovice, Czech Republic.

## E-mail address:

brabcova@zsf.jcu.cz

## Reprint address:

Iva Brabcova  
J. Boreckeho 27  
37011 Ceske Budejovice  
Czech Republic

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## Abstract:

**Objective:** Care of handicapped or elderly by the family members in the home environment brings not only many positives for the care recipients, but can also impose a significant burden on the caregiver. The goal of the study was to assess the caregiver burden, burnout syndrome and the effect of caregivers' sociodemographic characteristics.

**Design:** Cross-sectional study.

**Participants:** The sample consisted of 168 caregivers who took care of disabled children or seniors.

**Methods:** Zarit Burden Interview identifying the subjective burden of informal caregivers, and Maslach Burnout Inventory assessing the burnout syndrome were used.

**Results:** A higher level of caregiver burden and the development of burnout syndrome occurring most frequently in the dimensions of Emotional Exhaustion and Personal Accomplishment was observed. The caregiver burden was found to be lower in men, in caregivers living alone, and in the respondents from higher income households; it increased with the weekly amount of care.

**Conclusions:** The results prove the demanding nature of informal care. A longitudinal study could illuminate the temporal changes in the family dynamics.

## Introduction

Informal family care represents an important component in the long-term care system of a significant one not only in our country, but also in other European countries (Horová et al., 2021). In addition to chronic patients and disabled children, who are cared for by their parents, the ageing dependent adults rely on the informal caregiver network so that they can stay in their familiar setting and their communities. This dependency can cause considerable physical, psychological and financial problems to their caregivers, including their social isolation (Schulz & Sherwood, 2008; Schulz & Tompkins, 2010; Sallim et al., 2015; Loh et al., 2017, etc.).

Personal engagement, particularly the emotional engagement of individuals who take care of a dependent member of the family, can result in a caregiver burden, specifically manifested by stress. It is a condition in which the degree of burden is greater than the tolerable limit of the adaptation possibilities of the organism. In the course of stress, real or subjective demands exceed the individual's adaptation capabilities, or these capabilities are not fully used, and, as a result, the subjective comfort, health, and self-image are at risk (e.g., Hladký et al., 1993; Cohen et al., 1997; Boss, 2002; Paulík, 2020).

Burnout syndrome can develop in the course of long-term care of a disabled or ill person (Chang, 2011; Truzzi et al., 2012; Vévodová et al., 2016; de Souza Alves et al., 2019). Its development is influenced by several external and internal factors.

## Methods

The objective of the study was to identify the degree of subjectively experienced care burden in family caregivers in the region of South Bohemia in correlation with their sociodemographic profile and burnout syndrome. The study was designed as an observational study. The project was approved by the Research Ethics Committee of the Faculty of Health and Social Sciences, University of South Bohemia in České Budějovice (protocol no. 005/2019).

## Sociodemographic profile of the respondents

The sample consisted of 168 respondents chosen using a deliberate (systematic) sampling following defined criteria according to which the respondents were individuals aged 18+, with a permanent address in the South Bohemian Region, taking care of a spouse/child/relative with reduced self-sufficiency in the home setting for

minimally 8 hours a day. All respondents were informed about the goal of the study, also that their participation is voluntary and the data remain strictly confidential. The study was carried out in the second half of 2020.

In the sample, women outnumber men in the ratio of 139 women (82.7%) to 29 men (17.3%), following the traditional division of roles in the family. Part of the female role consists of the care of dependent family members (by mothers or daughters). The age ranged between 20 and 85 years, with a median age of 47 years (IQR 42–57).

In almost all cases, the length of care of a dependent person is long-term. Almost half of the respondents (42.3%) have been providing care for an extremely long time of more than 10 years; 13.7% of the respondents provide their care in the range between 6 and 10 years; 31.5% of caregivers have been providing care for 1 to 5 years; (12.5%) have been caring for their relative for less than a year. The number of hours consumed by care is very high, on average 58.6 hours per week, with a median of 40.0 hours. The demanding nature of the work of informal caregivers is increased by the fact that there are no fixed working hours.

## Measures

Two methods were used to obtain the data on family caregivers. First, the subjective burden of informal caregivers was explored by the Zarit Burden Interview (ZBI; Zarit et al., 1986; Czech translation by Topinková, 1995). The questionnaire assesses the degree of burden associated with the care of ill or disabled individuals with physical, sensory, or combined disorders. It contains 22 questions that express the most common feelings of people who take care for an elderly dependent relative. The questions relate to the feelings that accompany the care. They identify the degree of demandingness and perceived unpleasant duties. The intensity of the burden was assessed using a Likert scale in the range of 0 to 4.

Second, the Maslach Burnout Inventory (MBI; Maslach & Jackson, 1981) was used to assess burnout syndrome. The inventory contains 3 scales; each of them assesses a separate burnout dimension. The Emotional Exhaustion scale (EE) comprises 9 items that diagnose the intensity and frequency of the motivation effort, the degree of

fatigue, exhaustion, and life pessimism. The Depersonalization scale (DP) contains 5 items that assess changes in the quality of mental activity, i.e., apathy and estrangement, particularly in the interpersonal context. The Personal Accomplishment scale (PA) consists of 8 items to identify the subjective assessment of one's own abilities to deal with and positively influence problems. Note that the PA scale was inverted to have the same meaning as the other 2 scales (i.e., the higher the score, the more negative the assessment). So, Personal Non-achievement (PN) scale is used throughout the paper. The intensity of the feelings on all 3 scales was evaluated on a 7-point Likert scale.

Both measures were evaluated according to the authors' guidelines. Results are presented as frequencies (%) and means ( $\pm$ SD) or medians (Me; IQR) as appropriate. The effect of demographical factors on the results was studied using non-parametric tests (Mann-Whitney, Kruskal-Wallis). The correlations were analyzed using the Spearman's correlation coefficient. Results with  $p < 0.05$  were considered significant. IBM SPSS 26.0 statistical package was used for all analyses.

## Results

The data in Table 1 show that caregivers perceive their work as stressful, although to a different degree. Only 8.9% of the respondents find the burden very low; on the other hand, 3.6% of the respondents perceive a severe burden. The majority of respondents feel moderate burden (Me 38, IQR 29–47).

**Table 1** Distribution of the burden of care score assessed by the Zarit Burden Interview (ZBI) (N=168).

ZBI Score	Degree of burden	Frequency	Percentage
0–20	Little or no	15	8.9%
21–40	Mild to moderate	81	48.2%
<b>41–60</b>	<b>Moderate to severe</b>	<b>66</b>	<b>39.3%</b>
<b>61–x</b>	<b>Severe</b>	<b>6</b>	<b>3.6%</b>

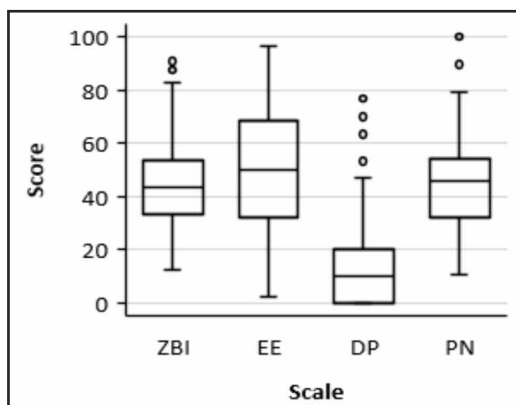
**Table 2** Distribution of the scores of the MBI subscales according to the degree of burnout (N = 168).

Scale	Score	Degree	Frequency	Percentage
EE	0–16	Low	40	23.8%
	17–26	Medium	41	24.4%
	27–x	Burnout	87	51.8%
DP	0–6	Low	132	78.5%
	7–12	Medium	26	15.5%
	13–x	Burnout	10	6.0%
PN	0–9	Low	17	10.2%
	10–16	Medium	32	19.0%
	17–x	Burnout	119	70.8%

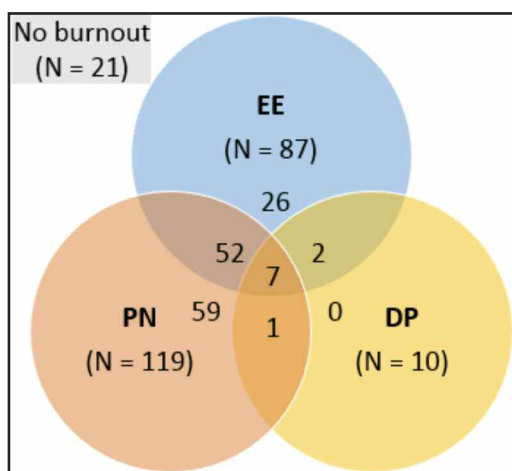
The variability of the 3 dimensions of the MBI scores is not homogeneous (Table 2; Figure 1); it is very high in the dimension Emotional Exhaustion (EE). The EE score ranges from 1 to 52 points; Me = 27 is located in the burnout zone (IQR 17.25–37). On the other hand, the variability of the Depersonalization (DP) score is much lower – more than three quarters of the respondents fit in the low degree of this dimension. The values range between 3 and 23, Me = 6, i.e., at the border-line of the low and medium depersonalization (IQR 0–6). Although the variability of the Personal Non-achievement (PN) scale score is again higher, most of the respondents belong to a high degree of burnout (see Table 2). The results range from 5 to 48 points. Me = 22 is in the zone of low burnout (IQR 15.25–26).

**Figure 1** Distribution of the 4 scale scores.

All scores were transformed to a 0–100 scale to aid the comparison (theoretical scale minimum = 0, and maximum = 100, respectively).



**Figure 2** Distribution of respondents with indicated burnout syndrome in the three dimensions of MBI (N = 168).



The MBI values show an extremely high degree of emotional exhaustion as a result of an excessively high work load. More than half of the EE scores (51.8%) are in the burnout category. DP score shows a different distribution, with burnout scores found only in a minority of caregivers. Most caregivers do not experience feelings of depersonalization or cynicism. Obviously, most caregivers do perceive their care as unsuccessful or insufficient. The actual burnout situation of informal caregivers is illustrated by summarizing the number of respective scales where the degree of burnout was achieved. Most of the respondents (87.5%) achieved high scores (i.e., burnout) on at least one scale. Approximately a third of them (32.7%) scored on 2 scales; 4.2% of caregivers scored on all 3 scales (Figure 2).

The effect of demographic factors was rather limited, with only the ZBI score showing some significant (but not very unexpected) results. The ZBI score was found to be different in male and female caregivers ( $p = 0.026$ ), with the male caregivers showing greater resistance to burden (Me 32, IQR 23–42) compared to women (Me 39, IQR 29–50). Additionally, the type of living (together with the care recipient or alone) affected the burden ( $p = 0.030$ ), which was lower in the caregivers living alone (Me 34, IQR 27–42, and Me 39, IQR 29–50, respectively). Finally, the ZBI score was positively correlated with the length of care in hours per week ( $r_s = 0.251$ ,  $p = 0.002$ ), and negatively with family income ( $r_s = -0.217$ ,  $p = 0.005$ ). Neither the total length of care nor the type of care recipient (children or older adults, respectively) showed any effect on the scores on any of the 4 scales.

The results of the correlation analysis among all the indicators studied (Table 3) suggest a positive relationship between the care burden (ZBI) and 2 of the MBI subscales: emotional exhaustion (EE) ( $r_s = 0.686$ ;  $p < 0.001$ ), and depersonalization (DP) ( $r_s = 0.449$ ;  $p < 0.001$ ).

**Table 3** Inter-scale correlations. Spearman's nonparametric correlation

	EE		DP		PN	
	$r_s$	$p$	$r_s$	$p$	$r_s$	$p$
ZBI	<b>0.686</b>	<b>&lt;0.001</b>	<b>0.449</b>	<b>&lt;0.001</b>	-0.017	0.831
EE			<b>0.313</b>	<b>&lt;0.001</b>	<b>-0.225</b>	<b>0.003</b>
DP					0.071	0.361

Bold depicts a significant correlation between the scores.

In terms of correlation within the burnout syndrome subscales, Emotional Exhaustion (EE) correlates positively with Depersonalization (DP) ( $r_s = -0.313$ ;  $p < 0.001$ ) and negatively with Personal Non-achievement (PN) ( $r_s = -0.225$ ;  $p < 0.01$ ). DP and PN do not show any significant relationship.

## Discussion

The acceptance of the commitment to take care of a disabled child or a dependent, often immobile, elderly person (a parent, a spouse) often means a considerable interference with the common functioning of the family. After accepting

this commitment, the caregiver (mostly a woman) becomes permanently overloaded, which can, over time, result in somatic and psychological exhaustion.

Informal care includes a number of difficult activities, the caregivers have to face a number of problems; therefore, it is perceived as demanding and stressful, although at different levels. Providing care overburdens caregivers physically (headaches, backaches, pain in muscles and joints, excessive fatigue, exhaustion, sleep disorders caused by frequent getting up due to positioning, transfers from the bed to the chair, drowsiness) and psychically leading to irritation, tension, anxiety, sadness, or depression. The frequency of physical and psychological problems is similar (78% & 77.4%). The total sum of problem cases (228.0 %) shows that family caregivers experience more than one sort of problem at a time, i.e., the problems are combined (the sum exceeds 100% since it was a multiple choice question). Similar results are mentioned by Salim et al. (2015), who, in their meta-analysis comprising 10,825 caregivers of patients with Alzheimer's disease, identified a higher prevalence of psychological problems, mental disorders, particularly depression and anxiety, compared to the general population. A higher prevalence was identified mainly in caregivers who take care of their spouses. The meta-analysis by Loh et al. (2017) in 1,756 caregivers of stroke patients also found a high prevalence of depression and anxiety signs (40.2 % and 21.4 %), particularly in female caregivers compared to male caregivers. The results were confirmed by a recent screening of 4,312 articles comprising 74 studies stating that informal care represents a significant determinant of emotional problems, particularly anxiety (del-Pino-Casado et al., 2021), and that long-term care can decrease the caregiver's quality of life.

In addition to physical and psychological problems, 67.7% of the respondents also experience social problems. They include reduced sociability, limited social contacts, lack of time for friends, for one's own hobbies, social apathy, lack of interest in the appreciation shown by other people. It seems that with increasing time consumed by the care, the caregiver's life is limited to the needs of care recipient. On the other hand, it can be caused by the fact that the care is



so exhausting that many caregivers lose interest in social contacts.

Intensive prolonged stress due to excessive psychological and emotional demands results in burnout syndrome in many informal caregivers. Under the influence of chronic stress and permanent problems and obstacles, the original interest, activity, and personal engagement develop into the belief that the expected effect does not appear despite all effort. Maslach and others (Maslach & Jackson, 1981; Maslach & Goldberg, 1998) described the 3 dimensions of burnout syndrome. This study identified high levels of emotional exhaustion (EE) with lack of energy in a larger proportion of the respondents: 51.8% of the respondents belong to the burnout category; 24.4 % occupy the medium degree of emotional exhaustion; only 23.8% of the respondents show a low degree of this burnout dimension. Informal caregivers are characterized by the feelings of weariness, loss of creativity, weakening, and fatigue. It is the expected result of the emotional engagement and emotional demandingness of the care. Empathic experiences of compassion with one's own ill children, powerless (infirm) parents or spouses, co-experiencing of their difficult life situations, are emotionally extremely exhausting. A high correlation between emotional exhaustion and caregiver burden ( $r_s = 0.686$ ;  $p < 0.001$ ) suggests that the caregiver's emotional exhaustion correlates with increased feelings of fatigue and inability to continue. Similar findings are mentioned, for example, by Truzzi et al. (2008), Valente et al. (2011), Otero (2016), who identified an exhaustion of emotional strength and an increase in depression in elderly adults. Other studies emphasized the correlation between burnout and anxiety. According to these studies, anxiety can be the result of the caregiver's emotional exhaustion; however, anxiety as a personality characteristic can also lead to greater reusability, considerateness, and self-denial, which allows the development of burnout.

The exhaustion dimension is often regarded as the strongest key burnout dimension, which can possibly represent all the phenomena. However, this reduction of the syndrome to only one dimension does not take into account the other dimensions of burnout and is therefore unsuitable. Individuals experiencing burnout have also lost their interest, enthusiasm, loyalty, motiva-

tion, and identification with their work (Leiter & Maslach, 2016).

The distribution of results of the second burnout dimension, depersonalization (DP), which represents the problems in dealing with other people, is quite different. Only 6% of caregivers score in the burnout zone; 78.5% are in the low DP zone. A considerably lower DP score in comparison with EE score can be seen in the inter-scale correlations: despite the fact that the correlation between DP and ZBI is significant, it is lower compared to the correlation between EE and ZBI ( $r_s = 0.449$  and  $0.686$ , respectively).

The results indicate that the majority of the respondents do not feel any cynicism toward the care recipients; do not experience feelings of depersonalization, any negative or inappropriate attitudes; any emotional deprivation; withdrawal; estrangement; any dehumanized perception. They do not perceive themselves as emotionally stupefied observers of care-providing activities with the loss of ideals and affiliation and nursing motivation. This positive result can be attributed in part to care recipients. The increased degree of depersonalization could be more likely expected in caregivers in institutional facilities where a certain distance from the clients is maintained (i.e., in the elderly homes, etc.), and where the depersonalization can serve as a stupefying psychological defense against an excessively high burden arousing feelings of threat. Some studies drew attention to the social and emotional distance that develops between caregivers and care recipients, as the caregivers try to maintain internal composure (Cross et al., 2018). A recent review of the literature has also shown a higher depersonalization score in caregivers of elderly adults with a limited self-sufficiency. A positive correlation between the indicators was identified: the higher the recipient's limitations (combined with their aggressiveness, irritability or abnormal motoric behavior, hallucinations in the case of dementia, etc.); the higher the caregiver burden (de Souza Alves et al., 2019). Caregivers start to ignore or even hate the help, which they have originally chosen voluntarily, and in the end the subjects of their care become victims of their cynicism, lack of interest, and aggression (Goodwin et al., 2017). However, respondents in our sample take care of their loved relatives, prevailingly their ill and disabled children (44.3%) or

parents (34.7%), and the mutual relationships of affiliation generate a very personal and not dehumanized attitude.

The score of the third dimension of the MBI, Personal Accomplishment (or as an inverse scale, Personal Non-achievement, PN), is related to the basic self-image of the individual regarding the value of their work and the quality of their contribution. The results suggest that the majority of caregivers assess their achievements as unsuccessful, decreasing their self-confidence, with insufficient results and poor quality of their contribution. On the other hand, in a limited number of caregivers providing care can mobilize psychological and physical reserves and result in the search for new ways to solve caregiving situations. The personal growth, which positively influences the care recipient is the topic of interest of some studies (see, e.g., Cross et al., 2018).

The view on the dimension of personal accomplishment has changed slightly in association with the development of the study of professional burnout (Schaufeli & Enzmann, 1998; Maslach et al., 2001; Leiter & Maslach, 2016). The above-mentioned authors regard personal accomplishment as a dimension that can outweigh the other two burnout dimensions – emotional exhaustion and depersonalization. In their study of the effect of psychological capital (PsyCap, summarizes hope, resilience, optimism, and self-efficacy) and caregiver load on the burnout, a lower weight of PA was found compared to the dimensions of EE and PD. It is pointed out that PA represents rather a personality factor that protects against burnout than a burnout dimension, and that this factor is, to a considerable degree, developed independently on the EE and DP. Our results correspond to this conclusion; the PN–EE correlation is significantly negative ( $r_s = -0.225$ ), which means that the decrease of personal non-achievement (i.e., increase in personal accomplishment) is related to the increase in emotional exhaustion and vice versa.

The results also show that the three burnout dimensions do not occur in a one-dimensional block, the inter-scale correlations do not have the same direction, and not all of them are high. Our results (low score of DP and high scores on the 2 remaining burnout dimensions) can be, in addition to others, explained by the Maslach process model (1982), which includes 3 phases of the

burnout development. In Phase 1, emotional exhaustion occurs as a reaction to excessive work demands. In Phase 2, depersonalization, the situation is tried to be managed by withdrawal or cynicism. As late as in Phase 3, in personal accomplishment, experiences of one's own failure appear in the self-assessment. From the point of view of the process model, respondents in our study are in the last phase of burnout, which would be in accord with the rather long-term care. But the length of care was surprisingly not in any way correlated with the scales (see above). This finding is of fundamental importance for the choice of suitable preventive, counseling, or therapeutic interventions.

Studies by Maslach & Leiter (2008) and Leiter & Maslach (2016) point out in this association that there may be several combinations of burnout dimensions, varying in time in dependence on situation factors, personal qualities, or their interactions. It is emphasized that there are differences between individuals who score in one respective burnout dimension but not in the other 2 dimensions, compared to a different 1:2 scenario; or they may score in all three dimensions. Although there is evidence that the burnout dimensions mostly increase and decrease concurrently (Maslach et al., 2001), their possible changes do not always occur at the same time. Studies by Maslach & Leiter identified, next to the 2 standard profiles on the Burnout/Engagement axis, 3 additional “inter-profiles”. Each of these inter-profiles has, similarly as in this study, a high score only in one burnout dimension. These are: Overextended (only high EE); Disengaged (only high PD); Ineffective (only high PN). All inter-profiles have their specifics: they distinguish themselves by different qualities in the area of experiencing and behavior; importantly from the point of view of providing care, they are less negative than the burnout profile. In this study, the Ineffective profile (high PN score, low EE and DP scores) prevailed in the respondents. Leiter & Maslach consider the Disengaged profile (high DP) to be the most negative pattern with regard to the social context of care, meaning that it is closer to burnout even than emotional exhaustion. In our study, less than 6% of the respondents match the disengaged profile. This rather positive result can help with the specification of counseling interventions and the way of

guiding self-help groups of family caregivers.

The limitations of this study consist of the cross-sectional character of this study, which does not allow one to create a coherent picture of a causal correlation between the relevant characteristics of the caregiver's family, in which the caregiver and the care recipient function, and the experience and perception of the caregiver burden. Longitudinal studies could lead to a deeper understanding of the developmental dynamics of the caregiver burden and burnout, including the variability of both aspects in dependence on a wider spectrum of variables that can relieve subjective caregiver burden and contribute to the support of the caregiver health.

## Conclusions

The results of this study drew attention to the correlations between the caregiver burden and burnout syndrome. Although the study did not unambiguously confirm a significantly higher level of burnout syndrome in the entire sample, the results show obvious symptoms in most of the respondents. Burnout syndrome is one of the major health problems since it causes high social expenses. Based on the current professional literature, it is desirable to start a systematic psychological study of the caregiver burden and burnout syndrome in family caregivers. It should rather be a longitudinal investigation including a deep analysis of relevant factors, particularly in, but also out of the family. The study pointed to the high caregiver burden associated with physical and psychological difficulties, for example the caregiver's anxiety. It also suggested that there is a necessity to provide the caregivers themselves with care, e.g., in the form of interventions focused on prevention using counseling, relaxation courses, developing needed skills, offering of self-help groups and virtual reality to decrease the stress accompanying the caregiver burden. Future studies could contribute to the understanding of potential consequences of informal caregiver burnout for the care recipients and the influence of the consequences for the health-care system. Future studies focused on the positive aspects of informal care could be beneficial in preventing the burnout syndrome. They could include the maintenance of physical and psychological efficiency, increasing trust in one's own abilities and caregiver success, and the satisfy-

ing meaningfulness of the caregiver's work. Finding and using psychological benefits can represent an important coping strategy for the management of caregiver stress.

## Conflicts of Interest

None declared.

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## Data Availability

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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