The well-being and burden of caregiving for patients with Parkinson's disease

Title: The well-being and burden of caregiving for patients with Parkinson's disease

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Abstract

Objectives: Well-being and positive psychological functioning may protect caregivers from experiencing burden. Despite this, research has scarcely explored these variables among caregivers of patients with Parkinson's disease (PD). This research endeavored (1) to measure differences in distress and well-being between caregivers of PD patients and caregivers assisting individuals suffering from non-neurodegenerative age-related health problems (controls); and (2) to evaluate the predictors of well-being, distress and caregiver burden in the total sample of caregivers.

Methods: The study has a cross-sectional design. 100 caregivers were recruited from centers for aging individuals. 50 caregivers assisted patients with PD while the other 50 were considered as controls. Participants completed self-report questionnaires concerning psychological well-being, life satisfaction, post-traumatic growth, distress and symptomatology. Multiple regression analysis was performed on the data set of the total sample ($N = 100$), exploring the possible predictors and correlates of caregiver burden.

Results: Caregivers who assisted patients with PD significantly experienced more depression, more distress and less well-being when compared to controls. The main

significant correlates of caregiver burden were older age, less psychological well-being and more depression.

Conclusions: PD caregivers reported more impairment in psychological well-being and higher rates of distress. In the total sample of caregivers (of patients with PD and of healthy individuals), depression and specific areas of well-being (environmental mastery, personal growth) correlated to the burden of caregiving. Psychosocial interventions focused on these dimensions may help caregivers to better cope with the possible burden of the assistance.

Keywords: well-being; life satisfaction; caregiver burden; depression; Parkinson's disease.

Introduction

Patients with Parkinson's disease (PD) require increasing assistance over the course of the illness and this aid is often provided by informal caregivers, a role that tends to be taken by patients' partners or by their adult child. Due to its clinical complexities, providing care to patients suffering from PD may be challenging.[1,2] Caregivers of PD patients have to deal with all the physical symptoms of the illness, such as difficulties in walking and the progressive loss of their assisted's autonomy.[3] As a consequence, caregivers are required to negotiate new social, familial and professional roles.

In addition, PD patients may also suffer from psychological symptoms such as emotional dysregulation. This stressful condition has been found to be associated with the onset of psychological and physical symptoms in caregivers as well.[1-3] Literature documented that higher levels of caregivers' burden were associated with the increased disability and with neuropsychiatric symptoms of PD patients . Caregivers' health is important not only for their own functioning, but also for its direct consequences on their assisted's health condition.[1-6] In conclusion, recent investigations documented the importance of considering not only caregivers' distress, but also their quality of life and well-being.[7]

These initial studies investigated well-being mostly by using measures of quality of life.[8] Another approach deriving from Positive Psychology also included the evaluation of subjective and psychological well-being, which can be considered as psychological resources to be used when dealing with chronic illnesses.[9-10] The former (subjective well-being) includes life satisfaction and positive emotions,[11] whereas the latter refers to existential dimensions of human functioning, such as personal growth and purpose in life.[12] Both subjective and psychological well-being have a buffering effect when dealing with stress.[12-15]

Furthermore, well-being dimensions have been found to protect from caregiver burden.[12-15] This buffering role was documented also among caregivers of PD patients, who experienced distress together with increased positive emotions,[16] and post-traumatic growth (PTG).[6,16-20] This latter dimension represents the possible positive personal changes that can occur in the aftermath of a stressful event. Recently, PTG has been studied also in chronic or life-threatening illnesses such as cancer or neurodegenerative disorders.[13,16-20]

These initial investigations included only small samples of caregivers of PD patients, without control groups.[21] The majority of the studies adopted a qualitative design. For instance, Habermann interviewed caregivers of patients with either PD or Alzheimer's disease and most of them reported that being able to provide care positively contributed to increased self-insight and life appreciation.[18] Parveen and Morrison included both caregivers of PD patients and caregivers of other types of chronic illnesses in their sample in order to study their perceived gains over time.[20] Researchers found that demographic factors (ethnicity, gender, and care-recipient diagnosis) accounted for a significant 12% of the variance in predicting caregivers' gains. However, these authors did not directly compare the different caregiver subsamples according to their recipients' diagnoses.

In order to address these limitations, the first aim of the present study is to measure differences in distress, caregiver burden and well-being between a sample of caregivers of PD patients and one of caregivers who assisted individuals reporting non-neurodegenerative illnesses. Based on previous studies , it was hypothesized that caregivers of PD patients would experience lower life satisfaction and quality of life, but higher existential well-being (post-traumatic growth and purpose in life) when compared to caregivers of patients with non-neurodegenerative diseases. However, it

was also hypothesized that caregivers of PD patients would report higher distress because of the greater efforts required in caregiving for a patient with a complex neurodegenerative illness, as PD.

In light of the paucity of studies on the relationships between well-being and caregiver burden, a second aim of this research was to evaluate the possible predictors of caregiver burden in the total sample of caregivers.

Methods

Participants

A total of 120 caregivers were initially recruited (recruitment took place from January 2018 until September 2018): 50 of them assisted individuals suffering from PD (CG_{PD}) and 70 of them provided assistance to aging individuals with non-neurodegenerative illnesses. This latter group was considered as control caregivers (CG_C).

The recruitment of caregivers of patients with PD was performed in a rehabilitation outpatient clinic, in Northern Italy, in accordance with the following inclusion criteria: 1) providing care to a relative with Parkinson's disease; 2) age range 18-85 years; 3) being devoid of any mental disorder or any cognitive problem as assessed by a psychologist during the recruitment process.

Control caregivers were recruited in leisure/recreational centers for older adults in Northern Italy. They were selected according to the following criteria: 1) providing care to a relative who suffered from age-related health conditions other than a neurodegenerative illness; 2) age range 18-85 years; 3) being devoid of any mental disorder or any cognitive problem, as assessed by a psychologist during the recruitment phase. Participants in the CG_C group were asked to provide information about their care

recipients' health conditions (e.g., cardiovascular or endocrine diseases as diabetes, hypertension or other age-related physical problems).

After explaining the study's purpose and methods, all caregivers were asked to participate on a voluntary basis and they accepted the participation by providing their written informed consent. In the CG_{PD} group, all recruited participants (n = 50) agreed to partake in the study. This group consisted of 38 women (76%) and 12 men (24%), aged 60.9 ± 13.6 years (age range = 33-84 years). A large majority of them was the husband/wife of the patient with PD, while only three were their sons/daughters. These three sons/daughter were not living with the PD patients but visited them at least once a day. The majority of PD patients was male (60%).

Out of the initial 70 caregivers recruited in the control group, eight caregivers were not included in the study as they did not meet the inclusion criteria. They suffered from a mental disorder or from a cognitive problem. Additionally, other 12 control caregivers were not included since their assisted relatives were diagnosed with a neurodegenerative disease. The final CG_C group included 50 caregivers: 32 were women (64%) and 18 men (36%), with a mean age of 59.2 ± 10.6 years (age range = 45-85 years). A large majority of them was the husband/wife of the assisted, while only two were their sons/daughters. These two sons/daughter were not living with the assisted but visited him/her at least once a day.

Measures

All participants completed the following self-report questionnaires:

Psychological Well-Being Scales (PWB)[22]: it is a self-report questionnaire, which consists of 42 items that describe the following six dimensions of psychological

well-being: autonomy (6 items), environmental mastery (6 items), personal growth (6 items), positive relations with others (6 items), purpose in life (6 items), and self-acceptance (6 items). Individuals answer to the content of each item on a six-point format ranging from 0 "strongly disagree" to 6 "strongly agree". Higher scores represent higher levels of well-being in each specific dimension. The sum of the different scales composes the PWB total score. The Italian version of the PWB scales has satisfactory test-retest reliability.[23] In the present study, the PWB total scale α was = 0.847 for CG_{PD}, and it was = 0.819 for CG_{C}.

Life Satisfaction (LS; Personal Wellbeing Index)[24]: it consists of a general single question for assessing life satisfaction: "Thinking about your own life and personal circumstances, how satisfied are you with your life as a whole?". Participants respond on a Likert scale from 0 "No satisfaction at all" to 10 "Completely satisfied". The Personal Wellbeing Index could be applied in its single item form as a global measure of life satisfaction. This modality is reliable and valid for research purposes in clinical and neurological settings both with patients and caregivers.[25,26]

Post-traumatic Growth Inventory (PTGI)[17]: this self-report questionnaire investigates how positively individuals change their self-identity, their relations with others and their meaning in life after experiencing a stressful event. In the present research, we asked participants to consider the onset of their assisted's illness as an anchor point. PTG is composed of 5 subscales, which represent different areas of personal change (i.e., relations with others, new possibilities, personal strengths, spiritual changes, and appreciation of life). PTG has a total of 21 items rated on a 6-point Likert scale, ranging from 0 = ''I did not experience this change as a result of my crisis'' to 5 = ''I experienced this change to a very great degree as a result of my crisis''. It is possible to calculate five separate scores (one for each of the five subscales

) and to sum them in the total PTG score. In previous study with medical populations, the PTGI showed good psychometric properties.[27] In the present study, α for PTG total scale was = 0.960 for CG_{PD}, and it was = 0.934 for CG_C.

The *Psychosocial Index* (PSI)[28]: it is a 52 item self-report questionnaire. Some items (items 1-20 and 44-51) derived from Kellner's Screening List for Psychosocial Problems and other items (30-37) from the Wheatley Stress Profile. The tool can provide an appraisal of perceived stress together with a first-line, comprehensive assessment in different area of functioning: well-being, distress, illness behavior, and quality of life. The majority of the items requires a yes/ no answer, while other items are rated on a Likert scale 0–3 (from ''not at all'' to ''a great deal''). It is possible to calculate five separate scores (one for each of the area of functioning) and to sum them in the total PSI score. In the present study, α for PSI total scale was = 0.856 for CG_{PD}, and it was = 0.911 for CG_C.

Symptom Questionnaire (SQ)[29]: this is a self-report consisting of 4 distress scales (anxiety, depression, somatization and hostility-irritability) and 4 associated scales of well-being (relaxation, contentment, physical well-being and friendliness). It has a total of 92 items that require a yes/no answer, according to the presence/absence of symptoms in the various subscales. Accordingly, the distress scales may score from 0 to 17, whereas the well-being scales from 0 to 6. An Italian validation revealed a good split-half reliability.[29] In the present study, α was = 0.850 for the anxiety total scale, it was = 0.820 for the depression total scale, it was = 0.849 for the somatization total scale, and it was = 0.782 for the hostility-irritability total scale for the CG_{PD}. For CG_C, α was = 0.862 for the anxiety total scale, it was = 0.820 for the depression total scale, it was = 0.849 for the somatization total scale, and it was = 0.782 for the hostility-irritability total scale.

For evaluating caregiver burden, caregivers were administered the following self-report measures: the *Parkinson' Disease Questionnaire 29 item carer-version (PDQ29)*[30] and the *Zarit Burden Interview* (ZBI).[31,32] The former (PDQ29) represents the most widely used measure of Parkinson's caregiver burden, whereas the *Zarit Burden Interview* (ZBI)[31,32] represents one of the most used questionnaires for evaluating general caregiver burden. The two measures were then merged into a single dimension of caregiver burden (to be used in the regression analysis).

The *Parkinson' Disease Questionnaire 29 item carer-version*[30]: it is a 29-item self-report questionnaire that was administered only to PD caregivers. It measures social and personal activities, anxiety and depression, self-care, and strain. These scales' scores can be summed into a single total index.[30] Caregivers could respond on a 5-point Likert scale from 0 (Never) to 4 (Always). The validation study displayed high internal consistency.[30] In the present study, α for PDQ29 total scale was = 0.976.

The *Zarit Burden Interview* (ZBI)[31,32]: it is a self-report for the general assessment of caregiver burden. In this research, its shortened 22-item version was administered to control caregivers. Answers are given on a 5-point Likert scale ranging from 0 (never) to 4 (almost always). Each item score can be summed in a total final score, which represents the level of burden, from low (score <20) to medium (21-40) to high (score>40). It has a good convergent validity and high internal consistency.[31] In the present study, α was = 0.835.

These assessment tools were administered in their validated Italian versions, that were previously translated, tested and validated by various research groups. [23,27, 28, 32]

Study design

The study has a cross sectional design. A comparative design was applied to compare the two caregiver groups in terms of distress, caregiver burden and well-being (first aim of the present investigation). Then, in order to evaluate the possible predictors of caregiver burden in the total sample of caregivers (N = 100), regression models were applied.

Statistical analyses

The socio-demographic characteristics of participants were analyzed using Chi Square tests for years of assistance and years of education and an univariate analysis of variance for age.

First, we analyzed differences between CG_{PD} and CG_C in PWBS, LS, PTG, PSI, and SQ by performing multivariate and univariate analyses of variance.

Then, we standardized the scores of the ZBI and PDQ29 and merged them into a new variable defined as "caregiver burden". Next, a four-step regression analysis (method enter) was performed in the total sample of caregivers with the new variable - caregiver burden "ZBI/PDQ29" - as a dependent variable, and the following variables as possible predictors: socio-demographic factors (gender, age, marital status, employment), type of assistance-related variables (years of assistance, group condition CG_{PD} vs CG_C), PWBS dimensions, Life Satisfaction, PTGI total score and SQ depression.

The partial eta-squared as a measure of effect size was calculated considering a value of 0.1 as a large effect, a value of 0.04 as a medium effect and a value of 0.01 as a small effect.[33] The Statistical Package for the Social Sciences (SPSS Version 23) was used for analyses.

Ethical considerations

The study follows the Declaration of Helsinki' principles. All caregivers voluntarily accepted to participate to the study by signing an informed consent.

The Ethical Committees of the rehabilitation center (where the recruitment of PD caregivers was performed) and of the leisure/recreational centers (where the recruitment of controls was performed) approved the research project.

Results

Table 1 shows descriptive statistics. Patients and controls did not differ in terms of mean age and of socio-demographic characteristics, with the sole exception of employment status.

With regard to the PWB scales, a one-way MANOVA revealed no significant differences between PD caregivers and controls (Wilks'λ = 0.938, $F_{6,92}$ = 1.009, p = 0.424, partial eta squared = 0.062). However, the univariate tests revealed significant differences in the PWB total score ($F_{1,92}$ = 5.485, p = 0.021), environmental mastery ($F_{1,92}$ = 5.849, p = 0.017) and self-acceptance ($F_{1,92}$ = 4.165, p = 0.044), where CG_{PD} reported lower scores (Table 2).

With regard to Life Satisfaction (LS), a univariate analysis of variance revealed that CG_{PD} reported significantly lower LS ($F_{1,98}$ = 6.472, p = 0.013) than CG_C (Table 2).

With regard to the Post-traumatic Growth Inventory (PTGI), a significant multivariate main effect between the two caregiver groups emerged with a one-way MANOVA (Wilks' λ = 0.843, $F_{5,94}$ = 3.491, p = 0.006, partial eta squared = 0.157). At univariate tests, differences were found for PTG relations ($F_{1,98}$ = 8.996, p = 0.003), new possibilities ($F_{1,98}$ = 11.077, p = 0.001), personal strengths ($F_{1,98}$ = 9.128, p = 0.003), appreciation of life ($F_{1,98}$ = 17.838, $p < 0.001$), and PTG total score ($F_{1,98}$ = 12.288, p =

0.001), where CG_C reported significantly higher growth than CG_{PD}. These differences were not found in PTG spirituality scale (Table 2).

With regard to the Psychosocial Index (PSI), a one-way MANOVA revealed no significant differences between the two groups (Wilks' $\lambda = 0.914$, $F_{5,94} = 1.764$, $p = 0.128$, partial eta squared = 0.086) (Table 2). The univariate tests revealed differences only for the well-being subscale ($F_{1,98} = 4.166$, $p = 0.044$), where CG_C reported higher scores (Table 2).

With regard to the Symptom Questionnaire (SQ), a one-way MANOVA revealed no significant differences between the two caregiver groups (Wilks' $\lambda = 0.915$, $F_{4,95} = 2.211$, $p = 0.074$, partial eta squared = 0.085). The two groups differed only in terms of depression ($F = 4.438$, $p = 0.038$), and the CG_C experienced lower scores (Table 2).

Finally, the regression analysis in the total sample with the ZBI/PDQ29 standardized score as dependent variable showed that variables included in the fourth model explained 49.2% of the variance ($F_{15,83} = 5.357$, $p < 0.001$) (Table 3). Particularly, age ($\beta = 0.306$, $p = 0.026$), PWB environmental mastery ($\beta = -0.354$, $p = 0.025$), PWB personal growth ($\beta = 0.352$, $p = 0.008$), and SQ depression ($\beta = 0.406$, $p = 0.001$) significantly predicted ZBI/PDQ29 total score (Table 3).

Discussion

This study aimed to evaluate differences in well-being and distress between a sample of caregivers of PD patients and a matched sample of caregivers of individuals with age-related health problems (non-neurodegenerative diseases). Findings confirmed that carers of individuals suffering from PD reported more distress and impairments in well-

being dimensions. Furthermore, PD caregivers showed higher levels of depression, when compared to caregivers of patients with non-neurodegenerative diseases.

PD caregivers reported impaired levels of general well-being (measured with the Psychosocial Index), impaired environmental mastery and self-acceptance (PWB subscales) and impaired life satisfaction, when compared to control caregivers. Only few investigations explored these dimensions in PD caregiver populations.[34] For instance, Smith and Shaw documented that PD caregivers reported well-being only when they were able to positively deal with their assisted's disease and when they were able to adjust to their partners' body modifications and loss of autonomy.[34] Similarly, the impairments in well-being that we observed in our sample of PD caregivers could be interpreted as a result of their difficulties in adapting to the illness. In other neurodegenerative disorders, such as Multiple Sclerosis (MS), some investigations reported that caregivers' well-being was impaired as a result of their negative emotional reaction to the disorder of the assisted person.[35,36] Conversely, PWB of caregivers of patients with MS was preserved when caregivers had a clear understanding of the illness and a sense of control over its course. These investigations highlighted that a clear understanding of the illness course, and a sense of confidence in dealing with the illness itself may result in a better sense of control and in the maintenance of caregivers' well-being.[35]

With regard to another indicator of well-being, i.e., life satisfaction, PD caregivers reported lower LS when compared to controls. Petrican et al.[16] investigated the role of LS in partners of PD patients. They observed that LS was higher in caregivers who were more able to differentiate negative vs positive emotions. Unfortunately, we did not examine this ability. However, we found that negative emotions (i.e., those referring to depressive symptoms), were higher in caregivers of PD

patients, when compared to controls (see Table 2). Similarly, Bassi et al.[35] found that life satisfaction was impaired in caregivers of individuals with MS who reported more negative emotional reactions to the disease of their assisted. Conversely, LS was higher in caregivers who believed that their assisted's health condition might be improved, and who were able to make sense of their assisted's illness.

We also measured other existential dimensions of well-being (e.g., post-traumatic growth). Few studies assessed PTG in caregivers of patients with PD. We compared the levels of caregivers' PTG with those of caregivers assisting patients with non-neurodegenerative disorders and we found that this dimension of existential well-being was impaired in caregivers of PD patients. This result disconfirmed either our initial hypothesis and previous studies, where caregivers of PD patients reported to experience existential benefits despite PD chronic and burdensome nature.[6,18-20] Mavandadi et al.[19] documented that these positive benefits may favor a better adjustment to the illness, may decrease depressive symptoms, and may amplify personal skills and resources. Moreover, the recognition of such existential benefits was found to be connected to the years from PD onset. Authors found that if a clear understanding of the disease contributed to the occurrence of positive changes initially, the intensity of caregiving and the use of coping strategies (self-distraction and denial) were the predictors of later positive changes .[19] These findings could explain the discrepancies between our results and those of Parveen and Morrison.[20] In fact, our caregivers have been assisting their relatives for a shorter period, when compared to those included in Parveen and Morrison's sample (6.1 years vs 9.9 years, respectively).[20] Our caregivers, thus, are in the initial phase of adaptation to the illness of their assisted. Therefore, it could be possible that they found more difficult to distil existential well-being and personal growth in this illness stage. Additionally, studies documented that the longer

time elapsed since the illness diagnosis, the greater the positive changes are.[9] This could be related to the process of cognitive accommodation, which was found to be essential for triggering PTG.[23,37] In this case, the process of accommodation might be only at an early stage for our sample of caregivers. Moreover, PD may have a gradual degenerative symptom progression in its initial stages, and caregivers may not have perceived or recognized its complexity, yet. This fact might hamper them from experiencing a sense of personal growth and purpose in life as it was reported in other chronic illnesses.[38] On the other hand, caregivers of individuals with other types of illnesses, such as cardiovascular problems, may experience positive psychological changes also in the initial phase of their assisted's illness.[38] This fact could provide explanation to the higher PTG reported by our group of control caregivers.

With regard to distress and psychological symptoms, our study confirmed previous investigations, where caregivers of PD reported more depression than caregivers of individuals with other types of illnesses.[1,2,39] Mood, emotional swings and affective disorders are reported as common symptoms experienced by patients with PD, also in the earlier stages of the illness. In line with the observation that the health condition of patients may affect the one of their caregivers (and vice versa),[1-6] it is possible that our PD caregivers reported higher levels of depression when compared to control caregivers, who assisted individuals devoid of such psychological distress.[2-6]

Control caregivers were recruited in leisure/recreational centers where various activities were performed (e.g., artistic activities, hobbies, cards, dance, etc.). These activities may entail the inclusion in a social network of caregivers, where they may have shared experiences of well-being and personal growth.[22,40-42] Conversely, Abendroth et al. found severe restrictions in the social, professional and leisure activities of PD caregivers.[39] These restrictions may hamper caregivers' chances to

experience well-being or other existential psychological changes.[39] As a consequence, PD caregivers may also have reported more depressive symptoms than controls.

Finally, the second aim of our study was to perform a regression analysis to evaluate the possible predictors of caregiver burden in the total sample of caregivers. This analysis found that age, well-being and depression predicted caregiver burden (Table 3). A direct relation between age and caregiver burden emerged. This result confirms previous findings showing that older caregivers reported more distress when compared to younger ones, since the former had to deal with their own age-related health problems.[3,6]

Furthermore, we also found that reduced levels of environmental mastery predicted higher caregiver burden in the total sample of caregivers. The dimension of environmental mastery is conceived as an individual attitude in selecting or adjusting environments according to personal needs.[12] It implies an active participation to life and the mastery of living conditions. Consequently, caregivers who lack this ability may be exposed to more burden.[37] Caregiver mastery was described as the "positive view of one's ability and ongoing behavior during the caregiving process".[43,44] Our findings, thus, may suggest that caregivers with more environmental mastery may report lower burden since they achieved a higher sense of control and self-efficacy during the caregiving processes.[43,44]

The regression model showed that caregiver burden was predicted also by personal growth, another core dimension of well-being. Higher personal growth was associated with higher burden. Even though this could be viewed as a counterintuitive result, previous research documented higher levels of personal growth in individuals who reported high levels of psychological distress.[27,40,45] For instance, previous research found that PTG could coexist with distress in cancer survivors or in patients with

chronic illnesses. [27,40,45] These findings may be in line with those emerged in our regression model, where caregiver burden significantly correlated to higher sense of growth.[27,40] Finally, depression emerged as another significant predictor of higher caregiver burden (see Table 3), and this data confirms existing literature. [46,47]

Our study was the first to investigate well-being dimensions together with distress in a sample of caregivers of PD patients. Additionally, we compared them with a sample of control caregivers of patients devoid of neurodegenerative disorders and found that PD caregivers were more vulnerable in terms of distress and well-being, particularly in its existential dimensions. Together with age and depression, these existential dimensions of well-being were the most significant predictors of caregiver burden. Importantly, our results highlighted that the type of illness of the patient assisted by caregivers is not directly connected to caregiver burden.

This study presents some limitations for its explorative nature and cross-sectional design. A limitation of the study is the small sample size and the restriction to one recruitment site for PD caregivers, which reduced the generalizability of the results. Only future replications with larger samples of caregivers and a longitudinal design may provide a better understanding of the relationships between burden and well-being and of their changes during the course of the illness. Moreover, only self-report measures were used. Furthermore, the duration of the caregiving was heterogeneous (6.1 ± 5.2 years) among our participants. Since this is an explorative investigation with a small sample, we could not control the large standard deviation within the statistical analyses. Finally, it was not possible to include an objective measure of the disability level of individuals assisted by caregivers. This measure would have provided a more comprehensive picture of our sample of caregivers.

Despite these limitations, the findings provide new insights on the importance of considering well-being dimensions among caregiver populations. Previous investigations assessed primarily their psychological distress and burden.[9,12,13] A sensitive recognition of impairments and vulnerabilities together with the assessment of well-being may pave the way for the development of interventions addressed at the promotion of skills and competencies, which could buffer from caregiver burden.[9,13] Our findings suggest that environmental mastery could be a crucial dimension associated with caregiver burden. Interventions focused on the alleviation of depression and on the promotion of environmental mastery (i.e., well-being therapy or other positive interventions) could have an important role in addressing caregiver burden.[48,49] Future trials and intervention studies are needed in order to verify this hypothesis.

Conflict of interest: none.

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Table 1. Socio-demographic characteristics of the sample (N=100)

	PD Caregivers (n=50) M (DS)		Controls (n=50) M (DS)		F
Age	60.8	13.6	59.2	10.6	0.484
Years of education	11.7	4.7	10.8	4.2	1.025
Years of assistance	6.2	5.0	8.8	10.3	2.740
	N (%)		N (%)		$\chi 2$
Gender					1.714
Men	12	24.0%	18	36.0%	
Women	38	76.0%	32	64.0%	
Employment					0.367
Retired	30	60.0%	27	54.0%	
Current employed	20	40.0%	23	46.0%	
Marital status					0.233
Unmarried	10	20.0%	12	24.0%	
Married	40	80.0%	38	76.0%	

Note. *p≤0.05, **p≤0.01; PD=Parkinson's Disease

Table 2. Differences between caregivers of patients with PD and caregivers of healthy individuals in PWBS, LS, PTG, PSI, and SQ

	PD Caregivers (n=50) M (DS)	Controls (n=50) M (DS)	Total sample (N=100) M (DS)	F	Partial Eta Square
PWB					
Autonomy	32.6 (5.9)	34.8 (6.9)	33.7 (6.5)	3.091	0.031
Environmental mastery	30.1 (7.2)	33.4 (6.1)	31.8 (6.8)	5.849*	0.057
Personal growth	31.4 (5.2)	33.0 (5.8)	32.2 (5.6)	2.160	0.022
Positive relations	34.3 (5.0)	35.6 (5.3)	35.0 (5.2)	1.691	0.017
Purpose in life	27.6 (6.6)	29.2 (6.1)	28.4 (6.4)	1.618	0.016
Self-acceptance	30.7 (7.3)	33.7 (7.1)	32.2 (7.3)	4.165*	0.041
PWB Total	186.7 (28.3)	199.7 (27.2)	193.3 (28.3)	5.485*	0.054
LS	6.8 (1.8)	7.6 (1.5)	7.2 (1.7)	6.472**	0.062
PTG					
Relations	14.3 (9.7)	19.4 (6.9)	16.9 (8.8)	8.996**	0.084
New possibilities	7.9 (6.1)	11.9 (5.7)	9.9 (6.2)	11.077**	0.102
Personal strengths	8.6 (5.3)	11.5 (4.3)	10.1 (5.0)	9.128**	0.085
Spirituality	3.1 (3.3)	4.3 (3.5)	3.7 (3.5)	2.768	0.027
Appreciation of life	5.6 (4.1)	8.9 (3.6)	7.2 (4.2)	17.838**	0.154
PTG Total	39.6 (25.5)	55.9 (20.7)	47.8 (24.5)	12.288**	0.11
Distress	8.5 (7.1)	8.2 (7.6)	8.4 (7.3)	1.690	0.017
AIB	0.6 (0.9)	0.9 (1.6)	0.8 (1.3)	1.794	0.018
Stress	1.8 (1.5)	1.9 (1.8)	1.8 (1.6)	0.094	0.001
Well-being	6.9 (2.0)	7.6 (1.7)	7.3 (1.8)	4.166*	0.041
QoL	2.3 (0.7)	2.5 (0.7)	2.4 (0.7)	1.690	0.017
PSI total	10.8 (7.8)	11.0 (9.8)	10.9 (8.8)	0.010	0.000
SQ					
Anxiety	6.5 (5.9)	4.8 (4.5)	5.7 (5.3)	2.532	0.025
Depression	6.0 (5.0)	4.2 (3.7)	5.1 (4.4)	4.438*	0.043
Somatiz.	7.9 (5.6)	7.6 (6.0)	7.7 (5.8)	0.075	0.001
Hostility-irritability	3.6 (4.1)	3.7 (3.4)	3.7 (3.7)	0.958	0.000

Note. *p≤0.05, **p≤0.01; PWB=Psychological Well-Being Scales; LS=Life Satisfaction; PTG=Posttraumatic Growth inventory; PSI=Psychosocial Index; AIB=Abnormal Illness Behavior; QoL=Quality of Life; SQ=Symptom Questionnaire; ZBI=Zarit Burnout Inventory; PDQ29=Parkinson's Disease Questionnaire – caregiver version; ZBI and PDQ29 scores were standardized and combined in order to be comparable.

Table 3. Regression models predicting caregiver burden (ZBI/PDQ29) in the total sample of caregivers (N=100)

	Model 1		*Model 2*		*Model 3*		*Model 4*	
	β	*p*	*β*	*p*	*β*	*p*	*β*	*p*
Gender	0.204	0.041	0.212	0.033	-0.001	0.989	-0.025	0.779
Age	0.412	0.006	0.484	0.002	0.316	0.031	**0.306**	**0.026**
Marital status	0.093	0.371	0.087	0.399	0.073	0.440	0.075	0.398
Employment	0.218	0.132	0.239	0.095	0.149	0.264	0.203	0.110
Years of assistance			-0.224	0.028	-0.067	0.507	-0.043	0.650
Group			-0.066	0.506	-0.133	0.155	-0.143	0.104
PWB autonomy					0.028	0.815	-0.029	0.803
PWB environmental mastery					-0.485	0.003	**-0.354**	**0.025**
PWB personal growth					0.387	0.006	**0.352**	**0.008**
PWB positive relations					0.096	0.419	0.135	0.230
PWB purpose in life					-0.265	0.020	-0.190	0.079
PWB self-acceptance					-0.195	0.267	-0.096	0.564
LS					-0.054	0.645	-0.001	0.996
PTG total					0.009	0.919	0.026	0.766
SQ depression							**0.406**	**0.001**
R^2	0.108		0.155		0.414		0.492	
R^2 change	0.070		0.099		0.317		0.400	
F value	2.854	0.028	2.802	0.015	4.247	<0.0001	5.357	<0.0001

Note. ZBI=Zarit Burnout Inventory; PDQ29=Parkinson's Disease Questionnaire – caregiver version. ZBI and PDQ29 scores were standardized and combined in order to be comparable. PWB=Psychological Well-Being Scales; LS=Life Satisfaction; PTG=Posttraumatic Growth inventory; SQ=Symptom Questionnaire. For gender: 1=men, 2=women; marital status: 1=married, 2=not married (unmarried, divorced, widow); employment: 1=unemployed/retired, 2=employed; Group: 1=Caregivers Controls, 2=Caregivers of patients with Parkinson's Disease. R^2 change for Model 1 indicates variance explained by socio-demographic factors (age). R^2 change for Model 2 indicates variance explained by condition of assistance-related variables (years of assistance) after controlling for socio-demographic factors. R^2 change for Model 3 indicates variance explained by PWB subscales after controlling for socio-demographic factors and condition of assistance-related variables. R^2 for Model 4 indicates variance explained by depression, after controlling for socio-demographic factors, condition of assistance-related variables, and PWB subscales.