

Alma Mater Studiorum Università di Bologna
Archivio istituzionale della ricerca

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

This is the final peer-reviewed author's accepted manuscript (postprint) of the following publication:

Published Version:

Vescovelli, F., Ruini, C. (2022). The well-being and burden of caregiving for patients with Parkinson's disease. SCANDINAVIAN JOURNAL OF CARING SCIENCES, 36(1), 49-58 [10.1111/scs.12962].

Availability:

This version is available at: <https://hdl.handle.net/11585/801652> since: 2024-08-23

Published:

DOI: <http://doi.org/10.1111/scs.12962>

Terms of use:

Some rights reserved. The terms and conditions for the reuse of this version of the manuscript are specified in the publishing policy. For all terms of use and more information see the publisher's website.

This item was downloaded from IRIS Università di Bologna (<https://cris.unibo.it/>).
When citing, please refer to the published version.

(Article begins on next page)

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

Running title: Wellbeing and burden in Parkinson caregivers

Word count: 4616 (excluding abstract, declaration and references)

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

1
2
3) and to sum them in the total PTG score. In previous study with medical populations,
4 the PTGI showed good psychometric properties.²⁷ In the present study, α for PTG total
5 scale was = 0.960 for CG_{PD}, and it was = 0.934 for CG_C.
6
7

8
9
10 The *Psychosocial Index* (PSI)²⁸: it is a 52 item self-report questionnaire. Some
11 items (items 1-20 and 44-51) derived from Kellner's Screening List for Psychosocial
12 Problems and other items (30-37) from the Wheatley Stress Profile. The tool can
13 provide an appraisal of perceived stress together with a first-line, comprehensive
14 assessment in different area of functioning: well-being, distress, illness behavior, and
15 quality of life. The majority of the items requires a yes/ no answer, while other items
16 are rated on a Likert scale 0–3 (from “not at all” to “a great deal”). It is possible to
17 calculate five separate scores (one for each of the area of functioning) and to sum them
18 in the total PSI score. In the present study, α for PSI total scale was = 0.856 for CG_{PD},
19 and it was = 0.911 for CG_C.
20
21
22
23
24
25
26
27
28
29
30
31
32

33 The *Symptom Questionnaire* (SQ)²⁹: this is a self-report consisting of 4 distress
34 scales (anxiety, depression, somatization and hostility-irritability) and 4 associated
35 scales of well-being (relaxation, contentment, physical well-being and friendliness). It
36 has a total of 92 items that require a yes/no answer, according to the presence/absence
37 of symptoms in the various subscales. Accordingly, the distress scales may score from 0
38 to 17, whereas the well-being scales from 0 to 6. An Italian validation revealed a good
39 split-half reliability.²⁹ In the present study, α was = 0.850 for the anxiety total scale, it
40 was = 0.820 for the depression total scale, it was = 0.849 for the somatization total
41 scale, and it was = 0.782 for the hostility-irritability total scale for the CG_{PD}. For CG_C, α
42 was = 0.862 for the anxiety total scale, it was = 0.820 for the depression total scale, it
43 was = 0.849 for the somatization total scale, and it was = 0.782 for the hostility-
44 irritability total scale.
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

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

1
2
3 The study has a cross sectional design. A comparative design was applied to compare
4
5 the two caregiver groups in terms of distress, caregiver burden and well-being (first aim
6
7 of the present investigation). Then, in order to evaluate the possible predictors of
8
9 caregiver burden in the total sample of caregivers ($N = 100$), regression models were
10
11 applied.
12
13
14
15
16

17 ***Statistical analyses***

18
19 The socio-demographic characteristics of participants were analyzed using Chi Square
20
21 tests for years of assistance and years of education and an univariate analysis of
22
23 variance for age.
24
25

26 First, we analyzed differences between CG_{PD} and CG_C in PWBS, LS, PTG, PSI,
27
28 and SQ by performing multivariate and univariate analyses of variance.
29
30

31 Then, we standardized the scores of the ZBI and PDQ29 and merged them into a
32
33 new variable defined as “caregiver burden”. Next, a four-step regression analysis
34
35 (method enter) was performed in the total sample of caregivers with the new variable -
36
37 caregiver burden “ZBI/PDQ29” - as a dependent variable, and the following variables
38
39 as possible predictors: socio-demographic factors (gender, age, marital status,
40
41 employment), type of assistance-related variables (years of assistance, group condition
42
43 CG_{PD} vs CG_C), PWBS dimensions, Life Satisfaction, PTGI total score and SQ
44
45 depression.
46
47
48

49 The partial eta-squared as a measure of effect size was calculated considering a
50
51 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
52
53 small effect.³³ The Statistical Package for the Social Sciences (SPSS Version 23) was
54
55 used for analyses.
56
57

58 ***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' $\lambda = 0.938$, $F_{6,92} = 1.009$, $p = 0.424$, 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' $\lambda = 0.843$, $F_{5,94} = 3.491$, $p = 0.006$, 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

1
2
3 patients, when compared to controls (see Table 2). Similarly, Bassi et al.³⁵ found that
4
5 life satisfaction was impaired in caregivers of individuals with MS who reported more
6
7 negative emotional reactions to the disease of their assisted. Conversely, LS was higher
8
9 in caregivers who believed that their assisted's health condition might be improved, and
10
11 who were able to make sense of their assisted's illness.
12
13

14 We also measured other existential dimensions of well-being (e.g., post-
15
16 traumatic growth). Few studies assessed PTG in caregivers of patients with PD. We
17
18 compared the levels of caregivers' PTG with those of caregivers assisting patients with
19
20 non-neurodegenerative disorders and we found that this dimension of existential well-
21
22 being was impaired in caregivers of PD patients. This result disconfirmed either our
23
24 initial hypothesis and previous studies, where caregivers of PD patients reported to
25
26 experience existential benefits despite PD chronic and burdensome nature.^{6,18-20}
27
28 Mavandadi et al.¹⁹ documented that these positive benefits may favor a better
29
30 adjustment to the illness, may decrease depressive symptoms, and may amplify personal
31
32 skills and resources. Moreover, the recognition of such existential benefits was found to
33
34 be connected to the years from PD onset. Authors found that if a clear understanding of
35
36 the disease contributed to the occurrence of positive changes initially, the intensity of
37
38 caregiving and the use of coping strategies (self-distraction and denial) were the
39
40 predictors of later positive changes.¹⁹ These findings could explain the discrepancies
41
42 between our results and those of Parveen and Morrison.²⁰ In fact, our caregivers have
43
44 been assisting their relatives for a shorter period, when compared to those included in
45
46 Parveen and Morrison's sample (6.1 years vs 9.9 years, respectively).²⁰ Our caregivers,
47
48 thus, are in the initial phase of adaptation to the illness of their assisted. Therefore, it
49
50 could be possible that they found more difficult to distil existential well-being and
51
52 personal growth in this illness stage. Additionally, studies documented that the longer
53
54
55
56
57
58
59
60

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

1
2
3 experience well-being or other existential psychological changes.³⁹ As a consequence,
4
5 PD caregivers may also have reported more depressive symptoms than controls.
6

7
8 Finally, the second aim of our study was to perform a regression analysis to
9
10 evaluate the possible predictors of caregiver burden in the total sample of caregivers.
11
12 This analysis found that age, well-being and depression predicted caregiver burden
13
14 (Table 3). A direct relation between age and caregiver burden emerged. This result
15
16 confirms previous findings showing that older caregivers reported more distress when
17
18 compared to younger ones, since the former had to deal with their own age-related
19
20 health problems.^{3,6}
21
22

23
24 Furthermore, we also found that reduced levels of environmental mastery
25
26 predicted higher caregiver burden in the total sample of caregivers. The dimension of
27
28 environmental mastery is conceived as an individual attitude in selecting or adjusting
29
30 environments according to personal needs.¹² It implies an active participation to life and
31
32 the mastery of living conditions. Consequently, caregivers who lack this ability may be
33
34 exposed to more burden.³⁷ Caregiver mastery was described as the “positive view of
35
36 one’s ability and ongoing behavior during the caregiving process”.^{43,44} Our findings,
37
38 thus, may suggest that caregivers with more environmental mastery may report lower
39
40 burden since they achieved a higher sense of control and self-efficacy during the
41
42 caregiving processes.^{43,44}
43
44
45

46
47 The regression model showed that caregiver burden was predicted also by
48
49 personal growth, another core dimension of well-being. Higher personal growth was
50
51 associated with higher burden. Even though this could be viewed as a counterintuitive
52
53 result, previous research documented higher levels of personal growth in individuals
54
55 who reported high levels of psychological distress.^{27,40,45} For instance, previous research
56
57 found that PTG could coexist with distress in cancer survivors or in patients with
58
59
60

1
2
3 chronic illnesses.^{27,40,45} These findings may be in line with those emerged in our
4 regression model, where caregiver burden significantly correlated to higher sense of
5 growth.^{27,40} Finally, depression emerged as another significant predictor of higher
6 caregiver burden (see Table 3), and this data confirms existing literature.^{46,47}
7
8
9

10
11
12 Our study was the first to investigate well-being dimensions together with
13 distress in a sample of caregivers of PD patients. Additionally, we compared them with
14 a sample of control caregivers of patients devoid of neurodegenerative disorders and
15 found that PD caregivers were more vulnerable in terms of distress and well-being,
16 particularly in its existential dimensions. Together with age and depression, these
17 existential dimensions of well-being were the most significant predictors of caregiver
18 burden. Importantly, our results highlighted that the type of illness of the patient
19 assisted by caregivers is not directly connected to caregiver burden.
20
21
22
23
24
25
26
27
28
29

30
31 This study presents some limitations for its explorative nature and cross-
32 sectional design. A limitation of the study is the small sample size and the restriction to
33 one recruitment site for PD caregivers, which reduced the generalizability of the results.
34 Only future replications with larger samples of caregivers and a longitudinal design may
35 provide a better understanding of the relationships between burden and well-being and
36 of their changes during the course of the illness. Moreover, only self-report measures
37 were used. Furthermore, the duration of the caregiving was heterogeneous (6.1 ± 5.2
38 years) among our participants. Since this is an explorative investigation with a small
39 sample, we could not control the large standard deviation within the statistical
40 analyses. Finally, it was not possible to include an objective measure of the disability
41 level of individuals assisted by caregivers. This measure would have provided a more
42 comprehensive picture of our sample of caregivers.
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

1
2
3 Despite these limitations, the findings provide new insights on the importance of
4
5 considering well-being dimensions among caregiver populations. Previous
6
7 investigations assessed primarily their psychological distress and burden.^{9,12,13} A
8
9 sensitive recognition of impairments and vulnerabilities together with the assessment of
10
11 well-being may pave the way for the development of interventions addressed at the
12
13 promotion of skills and competencies, which could buffer from caregiver burden.^{9,13}
14
15 Our findings suggest that environmental mastery could be a crucial dimension
16
17 associated with caregiver burden. Interventions focused on the alleviation of depression
18
19 and on the promotion of environmental mastery (i.e., well-being therapy or other
20
21 positive interventions) could have an important role in addressing caregiver burden.^{48,49}
22
23
24
25
26 Future trials and intervention studies are needed in order to verify this hypothesis.
27
28
29

30 **Conflict of interest:** none.
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

References

1. Leiknes I, Tysnes OB, Aarsland D, Larsen JP. Caregiver distress associated with neuropsychiatric problems in patients with early Parkinson's disease: the Norwegian ParkWest study. *Acta Neurol Scand* 2010;122:418-424.
2. Santos-García D, De la Fuente-Fernández R. Factors contributing to caregivers' stress and burden in Parkinson's disease. *Acta Neurol Scand* 2015;131:203-210.
3. Glozman JM. Quality of life of caregivers. *Neuropsychol Rev* 2004;14:183-196.
4. Park J, Tolea MI, Arcay V, Lopes Y, Galvin JE. Self-efficacy and social support for psychological well-being of family caregivers of care recipients with dementia with Lewy bodies, Parkinson's disease dementia, or Alzheimer's disease. *Soc Work Ment Health* 2019;17:253-278.
5. Mosley PE, Moodie R, Dissanayaka N. Caregiver burden in Parkinson Disease: A critical review of recent literature. *J Geriatr Psychiatry Neurol* 2017;30:235-252.
6. Tan SB, Williams AF, Morris ME. Experiences of caregivers of people with Parkinson's disease in Singapore: a qualitative analysis. *J Clin Nurs* 2012;21:2235-2246.

7. Faronbi JO (2018). Correlate of burden and coping ability of caregivers of older adults with chronic illness in Nigeria. *Scand J Caring Sci* 2018;32:1288-1296.
8. Balash Y, Korczyn AD, Migirov AA, Gurevich T. Quality of life in Parkinson's disease: A gender-specific perspective. *Acta Neurol Scand* 2019.
9. Vescovelli F, Sarti D, Ruini C. Subjective and psychological well-being in Parkinson's Disease: A systematic review. *Acta Neurol Scand* 2018;138:12-23.
10. Fianco A, Sartori RD, Negri L, Lorini S, Valle G, Delle Fave A. The relationship between burden and well-being among caregivers of Italian people diagnosed with severe neuromotor and cognitive disorders. *Res Dev Disabil* 2015;39:43-54.
11. Diener E, Suh EM, Lucas RE, Smith HL. Subjective well-being: Three decades of progress. *Psychol Bull* 1999;125:276-302.
12. Ryff CD. Psychological well-being revisited: Advances in the science and practice of eudaimonia. *Psychother Psychosom* 2014;83:10-28.
13. Autio T, Rissanen S. Positive emotions in caring for a spouse: a literature review. *Scand J Caring Sci* 2018;32:45-55.
14. Cassidy T. Benefit finding through caring: The cancer caregiver experience. *Psychol Health* 2013;28:250-266.
15. Corallo F, De Cola MC, Lo Buono V, Di Lorenzo G, Bramanti P, Marino S. Observational study of quality of life of Parkinson's patients and their caregivers. *Psychogeriatrics* 2017;17:97-102.
16. Petrican R, Moscovitch M, Grady C. Proficiency in positive vs. negative emotion identification and subjective well-being among long-term married elderly couples. *Front Psychol* 2014;5:338.

17. Tedeschi RG, Calhoun LG. The Posttraumatic Growth Inventory: Measuring the positive legacy of trauma. *J Trauma Stress* 1996;9:455-471.
18. Habermann B, Hines D, Davis LL. Caring for parents with neurodegenerative disease: a qualitative description. *Clin Nurse Spec* 2013;27:182-187.
19. Mavandadi S, Dobkin R, Mamikonyan E, Sayers S, Ten Have T, Weintraub D. Benefit finding and relationship quality in Parkinson's disease: A pilot dyadic analysis of husbands and wives. *J Fam Psychol* 2014;28:728-734.
20. Parveen S, Morrison V. Predicting caregiver gains: A longitudinal study. *Br J Health Psychol* 2012;17:711-723.
21. Aneshensel CS, Pearlin LI, Mullan JT, Zarit SH, Whitlatch CJ. Profiles in caregiving: The unexpected career. Academic Press; 1995.
22. Ryff CD. Happiness is everything, or is it? Explorations on the meaning of psychological well-being. *J Pers Soc Psychol* 1989;57:1069-1081.
23. Ruini C, Ottolini F, Rafanelli C, Ryff CD, Fava GA. La validazione italiana delle Psychological Well-being Scales (PWB). *Riv Psichiatri* 2003;38:117-130. [article in Italian]
24. International Wellbeing Group. Personal Wellbeing Index: 5th Edition. Melbourne: Australian Centre on Quality of Life, Deakin University. Retrieved from <http://www.deakin.edu.au/research/acqol/instruments/wellbeing-index/index.php> Accessed 8 September 2019.
25. Vescovelli F, Sarti D, Ruini C. Well-being and distress of patients with Parkinson's disease: a comparative investigation. *Int Psychoger* 2019;31:21-30.
26. Hammond T, Weinberg MK, Cummins RA. The dyadic interaction of relationships and disability type on informal carer subjective well-being. *Qual Life Res* 2014;23:1535-1542.

27. Ruini C, Vescovelli F, Albieri E. Post-traumatic growth in breast cancer survivors: new insights into its relationships with well-being and distress. *J Clin Psychol Med Settings* 2013;20:383-391.
28. Sonino N, Fava GA. A simple instrument for assessing stress in clinical practice. *Postgrad Med J* 1998;74:408-410.
29. Kellner R. A symptom questionnaire. *J Clin Psychiatry* 1987;48:268-274.
30. Morley D, Dummett S, Kelly L, Peters M, Dawson J, Fitzpatrick R, Jenkinson C. The PDQ-Carer: development and validation of a summary index score. *Parkinsonism Relat Disord* 2013;19:448-449.
31. Zarit SH, Reeve KE, Bach-Peterson J. Relatives of the impaired elderly: correlates of feelings of burden. *Gerontologist* 1980;20:649-655.
32. Chattat R, Cortesi V, Izzicupo F, Del Re ML, Sgarbi C, Fabbo A, Bergonzini E. The italian version of the Zarit Burden interview: a validation study. *Int Psychogeriatr* 2011;23:797-805.
33. Huberty CJ. A history of effect sizes indices. *Educ Psychol Meas* 2002;62:227–240.
34. Smith LJ, Shaw RL. Learning to live with Parkinson's disease in the family unit: an interpretative phenomenological analysis of well-being. *Med Health Care Philos* 2017;20:13-21.
35. Bassi M, Falautano M, Cilia S, et al. Illness perception and well-being among persons with multiple sclerosis and their caregivers. *J Clin Psychol Med Settings* 2016;23:33-52.
36. Ghasemi M, Gorji Y, Ashtar F, Ghasemi M. A study of psychological well-being in people with multiple sclerosis and their primary caregivers. *Adv Biomed Res* 2015;4:49.

37. Joseph S, Becker S, Elwick H, Silburn R. Adult carers quality of life questionnaire (AC-QoL): development of an evidence-based tool. *Ment Health Rev* 2012;17:57-69.
38. Hamama L, Sharon M. Posttraumatic growth and subjective well-being among caregivers of chronic patients: A preliminary study. *J Happiness Stud* 2013;14:1717-1737.
39. Abendroth M, Lutz BJ, Young ME. Family caregivers' decision process to institutionalize persons with Parkinson's disease: A grounded theory study. *Int J Nurs Stud* 2012;49:445-454.
40. Barskova T, Oesterreich R. Post-traumatic growth in people living with a serious medical condition and its relations to physical and mental health: A systematic review. *Disabil Rehabil* 2009;31:1709-1733.
41. Kales H. To change the things we can: Aging well through self-acceptance, adaptation and continual growth. *Aging Today* 2014;35:8-9.
42. Ozanne OA, Graneheim UH, Persson L, Strang S. Factors that facilitate and hinder the manageability of living with amyotrophic lateral sclerosis in both patients and next of kin. *J Clin Nurs* 2012;21:1364-1373.
43. Tuomola J, Soon J, Fisher P, Yap P. Lived experience of caregivers of persons with dementia and the impact on their sense of self: A qualitative study in Singapore. *J Cross Cult Gerontol* 2016;31:157-172.
44. Lawton MP, Kleban MH, Moss M, Rovine M, Glicksman A. Measuring caregiving appraisal. *J Gerontol* 1989;44:61-71.
45. Ruini C, Albieri E, Vescovelli F. Post-traumatic growth, psychological well-being, and distress. In Martin CR, Preedy VR, Patel VB. (Eds.): *Comprehensive*

- 1
2
3 Guide to Post-Traumatic Stress Disorder. Switzerland: Springer International
4
5 Publishing; 2016. pp.1731-1754.
6
7
8 46. Adelman RD, Tmanova LL, Delgado D, Dion S, Lachs MS. Caregiver burden: a
9
10 clinical review. *Jama* 2014;311:1052-1060.
11
12 47. Genç F, Yuksel B, Tokuc FEU. Caregiver burden and quality of life in early and
13
14 late stages of idiopathic Parkinson's Disease. *Psychiatry Investig* 2019;16:285-291.
15
16 48. Ruini C, Albieri E, Vescovelli F. Well-being therapy: state of the art and clinical
17
18 exemplifications. *J Contemp Psychother* 2015;45:129-136.
19
20 49. Shin JY, Choi SW. Interventions to promote caregiver resilience. *Curr Opin*
21
22 *Support Palliat Care* 2020;14:60-66.
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

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 (%)		χ^2
Gender					1.714
<i>Men</i>	12	24.0%	18	36.0%	
<i>Women</i>	38	76.0%	32	64.0%	
Employment					0.367
<i>Retired</i>	30	60.0%	27	54.0%	
<i>Current employed</i>	20	40.0%	23	46.0%	
Marital status					0.233
<i>Unmarried</i>	10	20.0%	12	24.0%	
<i>Married</i>	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)	Controls (n=50)	Total sample (N=100) M (DS)	F	Partial Eta Square
PWB	M (DS)	M (DS)			
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. * $p \leq 0.05$, ** $p \leq 0.01$; 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)

	<i>Model 1</i>		<i>Model 2</i>		<i>Model 3</i>		<i>Model 4</i>	
	β	<i>p</i>	β	<i>p</i>	β	<i>p</i>	β	<i>p</i>
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	
<i>F</i> 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.