

## Caregiver-burden in parkinson's disease is closely associated with psychiatric symptoms, falls, and disability

Anette Schrag<sup>a,b</sup>, Anna Hovris<sup>b</sup>, David Morley<sup>b</sup>, Niall Quinn<sup>b</sup>, Marjan Jahanshahi<sup>b,\*</sup>

<sup>a</sup>Royal Free and University College Medical School, University College London NW3 2PF, London, UK

<sup>b</sup>Institute of Neurology, University College London, London WC1 N3BG, UK

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### Abstract

The majority of care of patients with Parkinson's disease (PD) is provided by informal caregivers; their caregiving not only offers physical and emotional support for patients but also plays a large economic role and prevents early nursing home placement. In order to support caregivers in this role, it is necessary to understand the extent of caregiver-burden and factors associated with increased caregiver-burden and distress. We therefore conducted a postal survey in 123 caregivers of patients with PD to assess caregiver-burden and factors associated with it. The majority of caregivers were female (66%). Over 40% of caregivers indicated that their health had suffered as a result of caregiving, almost half had increased depression scores, and two-thirds reported that their social life had suffered. After adjustment of disease duration, there was no difference in caregiver-burden between younger and older caregivers, or between male and female caregivers. Caregiver-burden increased with increasing disability and symptoms of PD, particularly with mental health problems such as depression, hallucinations, or confusion, and with falls. Caregiver-burden scores also correlated significantly with the patients' depression and quality of life scores, and with caregivers' own satisfaction with their marital and sexual relationship. We conclude that more attention should be paid to caregivers' emotional and physical health, particularly in advancing PD with psychiatric complications and falls. These findings also demonstrate that caregiver and patient quality of life are closely linked and emphasize the importance of including caregiver-burden among the problems associated with PD in order to improve patient and caregiver lives.

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**Keywords:** Parkinson's disease; quality of life; caregivers burden; depression

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### 1. Introduction

The burden of caring for a person with chronic disease such as Parkinson's disease (PD) is largely born by informal caregivers. Their number is likely to rise with an increasingly aging society, and the large economic contribution to society these informal caregivers provide is therefore likely to increase. However, the burden of caring for a person with chronic disease is associated with persistent stress and impaired psychosocial functioning of caregivers [1–3]. There is also evidence that having a caregiver is associated

with better outcome in terms of morbidity, mortality and quality of life of the patient [4], and caregiver distress is a major predictor for institutionalisation [5–9]. In order to effectively alleviate the impact of PD on the caregiver, which may not only improve caregiver quality of life, but also delay nursing home placement and improve patient outcome [10], it is necessary to assess the areas of greatest impairment and associated disease-related and -unrelated factors to allow for appropriate resource allocation to ameliorate distress and psychosocial impact of caregiving for patient with PD.

Whilst a number of studies have addressed caregiver-burden in PD, most of these had a small sample size or assessed only specific aspects of caregiver-burden or associated factors [3,11–19]. Thus, psychiatric morbidity has been reported to be more common in caregivers of patients with PD than in controls [11,17], level of pessimism has been found to be a predictor of poor caregiver quality of life [12], caregiver strain has been shown to increase with disease progression [14,18], and impaired verbal

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\* Corresponding author. Address: Sobell Department of Motor Neuroscience and Movement Disorders, Institute of Neurology, Queen Square, University College London, London WC1N3BG, UK. Tel.: +44 20 7837 3611/3055; fax: +44 20 7278 9836.

E-mail address: [m.jahanshahi@ion.ucl.ac.uk](mailto:m.jahanshahi@ion.ucl.ac.uk) (M. Jahanshahi).

communication and mental status have been found to be associated with poorer caregiver quality of life [13,15]. However, no study has assessed the overall impact of multiple disease-related and psychosocial factors on several measures of caregiver(s) quality of life in a large sample, and assessed the relationship between caregiver(s) and patients' quality of life. We therefore conducted a survey on the physical, emotional and social aspects of caring for patients with PD and on the associated factors of caregiver-burden in a large sample of caregivers of patients with PD.

## 2. Material and methods

This study was part of a wider study investigating the impact of PD on patients and their families [20,21]. Participants were recruited from two sources: First, we invited patients attending the PD clinics at the National Hospital for Neurology and Neurosurgery (NHN) to participate themselves and/or their families or caregivers to participate. As the database stretched back over more than two decades and addresses were incomplete in many cases, it was anticipated that many patients would not receive the letter of invitation. Letters of invitation were sent to 563 patients of whom 157 agreed to participate and 10 declined. A further 19 patients had died, and 17 had their postal invitation returned by the Post Office. In order to increase the number, we also advertised the study in the magazines and websites of UK patient support organizations. Fifty-seven patients or family members volunteered to participate after reading advertisements for this study.

Caregivers and patients who volunteered to participate were sent questionnaires on demographic, occupational and marital status as well as instruments to measure psychosocial variables (detailed below), and a stamped addressed return envelope. The study was approved by the Joint Research Ethics Committee of the NHN and the Institute of Neurology.

### 2.1. Instruments

#### 2.1.1. Measures of caregiver-burden and psychosocial variables

Caregiver quality of life was assessed using the Scale of Quality of Life of Care-Givers (SQLC), which was designed specifically for caregivers of patients with PD to assess the occupational, social and leisure activities of the caregiver and their responsibilities for the patient in everyday living [22]. The maximum score of 149 indicates the highest level of social adaptation of caregivers. In addition, we employed the Caregiver-burden Inventory (CBI) [23], a multidimensional measure of caregiver-burden. It comprises 24 questions in five domains (time-dependency burden, developmental burden, physical burden, social burden and emotional burden), which are rated on a 4-point scale. Higher scores indicate greater caregiver-burden. Depressive symptoms

were measured using the Beck Depression Inventory (BDI) [24], a 21-item questionnaire with scores ranging from 0 to 63, with higher scores indicating higher levels of depression. Total scores from 0–9 reflect no, scores of 10–18 indicate mild to moderate, scores of 19–29 reflect moderate to severe, and scores of 30–63 indicate severe depression. Marital satisfaction was assessed using the Marital Satisfaction Scale [25], a 4-item questionnaire with 10-point scales for separate ratings of satisfaction with the marital and sexual relationship, marital discord, and the degree of emotional upset caused by marital discord. Higher scores indicate greater satisfaction with marital and sexual satisfaction for items 1 and 2, and greater and more upsetting discord for items 3 and 4. The Short Social Support Questionnaire (modified from [26,27]) asks subjects to list a maximum of 9 people upon whom they can count for practical (item 1) and for emotional support (item 2). Participants are also asked to rate their satisfaction with practical or emotional support on a six-point scale, with higher scores indicating greater satisfaction.

#### 2.1.2. Measures of patients' disease severity, disability and psychosocial well-being

Disease severity and disability were assessed using self-administered, modified versions of the *Hoehn and Yahr scale* (with stage 0 indicating no parkinsonism and stage 5 indicating the most severe disease) and the *Schwab and England scale* (with 100 indicating complete independence and 0 indicating complete dependence). Agreement between clinician and patient ratings in a previous sample of patients with PD has been found to be high (intraclass correlation coefficient 0.70 for the Hoehn and Yahr scale and 0.82 for the Schwab and England scale [21]). Patients were also asked about the presence or absence of key symptoms of PD (falls, confusion, forgetfulness, bladder problems, sweating, sadness/depression, hallucinations, motor fluctuations and involuntary movements other than tremor) within the past 3 months. Health-related quality of life (Hr-QoL) in patients was assessed with the Parkinson's disease-specific PDQ-39 [28]. It comprises 39 questions with five different answer options, from which eight subscores (mobility, activities of daily living, emotional well-being, stigma, social support, cognition, communication, and bodily discomfort) and one summary index can be calculated (the maximum score 100 indicating worst level of problem). Patients were also asked to complete the BDI.

### 2.2. Statistical analysis

Data were inspected for normality of distribution and transformed where appropriate. If normality was not achieved using transformation of data, non-parametric tests were used. Categorical data were compared using Chi-square tests and continuous variables using t-tests or Mann–Whitney tests. Correlation were performed using Pearson's or Spearman rank correlations. All tests were 2-tailed. Significance level was  $p < 0.05$ , but Bonferroni correction was applied to adjust for multiple comparisons.

Thus, the significance level 0.05 for each set of tests was divided by the number of separate statistical tests.

### 3. Results

#### 3.1. Participants

One hundred and twenty three caregivers completed the questionnaires, 91 of whom we could match to questionnaires from patients. One hundred and four caregivers (86.7%) were spouses, 12 (10.0%) partners, two were recently widowed but had still completed the form, one caregiver was a parent, and four had another relationship to the patient. In order to achieve homogeneity of the sample, we restricted the analysis to the spouses and partners of patients ( $n=116$ ). Clinical and demographic characteristics of caregivers and patients are shown in Table 1.

#### 3.2. Extent of caregiver-burden

Thirty three percent of caregivers indicated that they themselves suffered from an illness, most commonly hypertension, thyroid problems, depression, arthritis, osteoporosis, asthma and back problems. The mean SQLC score

was 113.8 (SD 20.8); 51% reported that they felt physically tired as a result of caring, 42% of caregivers indicated that their health had suffered to some degree as a result of caring and 27% felt that caring had made them physically ill; 25% reported that their relationship with other family members had suffered, another 25% felt that their marriage had deteriorated to some degree and 65% felt that their social life had suffered; twenty seven percent reported that the caregiving role made them depressed. Caregiver quality of life scores correlated negatively with caregiver-burden scores ( $-0.75$ ) and with depression scores as measured on the BDI ( $-0.47$ ), which correlated positively with caregiver-burden scores ( $0.71$ ; all  $p<0.0001$ ). The mean BDI score was 8.5 (SD 6.5). Almost half of all caregivers (47%) had increased depression scores on the BDI (BDI score  $>9$ ), with 7% being moderately depressed (BDI score 19–29). On average, caregivers reported a satisfactory marital relationship (mean 8.3, SD 2.1) and a moderately satisfactory sexual relationship (mean 5.2, SD 3.7). Marital discord scores were low (mean 3.1, SD 2.6) and levels of upset due to discord were moderate (mean 6.1, SD 3.3). Caregivers reported that they received practical support from an average of 3.5 (SD 2.7) people and emotional support from a mean of 3.0 (SD 2.6) people. They were on average fairly satisfied with the practical and emotional support they received (mean scores 5.0 (SD 1.4) and 4.9 (SD 1.5)).

Table 1  
Characteristics of caregivers and patients

	Mean (SD) or percentage
Caregivers	
Caregiver age (years)	59.7 (10.6)
Female:male	77 (66%):39 (33%)
Years of marriage	31.2 (13.0)
Number of children	2.1 (1.2)
Patients	
Patient age (years)	59.8 (11.5)
Disease duration (years)	10.9 (7.7)
Hoehn and Yahr score	2.6 (1.5)
Percent time spent in "Off"	34.3 (23.7)
Self-assessed Schwab and England disability score (range 0–100)	67 (25.0)
Parkinson's Disease Quality of Life Questionnaire (PDQ-39) score	25.6 (16.1)
Beck depression inventory (BDI)	14.2 (8.6)
Percentage of patients reporting	
Falls	36%
Confusion	34%
Forgetfulness	62%
Bladder control problems	34%
Increased sweating	42%
Having felt sad or in a depressed mood for longer than two weeks	66%
	31%
Hallucinations	30%
Involuntary movement other than tremor	57%
related to medication	31%
Hour-to-hour fluctuations in their physical state attributed to medication	59%
	43%

SD, standard deviation.

#### 3.2.1. Correlations of caregiver-burden with demographic, disease-related, and psychosocial variables in patients and caregivers

1. *Demographic variables.* The mean SQLC and CBI scores did not differ between males and females, but caregiver BDI scores tended to be higher in female caregivers (9.3 (6.4) vs 7.2 (6.5),  $p=0.06$ ). After adjusting for disease duration there was no correlation between caregiver burden or depression scores and patient or caregiver age.
2. *Disease-related variables.* Poorer caregiver-burden scores were significantly associated with greater patients' disease duration, severity and disability (Table 2). The disease symptoms most strongly associated with greater caregiver-burden were mental health problems, including hallucinations, episodes of confusion, and depression, and the presence of falls (Table 3).
3. *Psychosocial factors in patients.* Poorer caregiver-burden and depression scores were significantly correlated with worse Hr-QoL and depression scores of patients (Table 4).
4. *Psychosocial factors in caregivers.* There was no correlation between caregiver-burden scores and years of marriage, but there was a significant correlation with caregivers' depression scores and with scores of satisfaction with the sexual and marital relationship

Table 2

Correlations of measures of caregiver burden and depression scores with patients' disease characteristics

	Scale of Quality of Life of Care – givers	Caregiver Burden Inventory	Caregivers' Beck Depression Inventory
Disease duration	−0.51*	0.39*	0.19
Hoehn and Yahr stage	−0.54*	0.50*	0.33*
Schwab and England score	0.75*	−0.61*	−0.25*
Percentage of day spent in 'Off'	−0.36*	0.57*	0.37*

\* $p < 0.0041$  (Bonferroni-adjusted).

(Table 5). The number of children and of people giving practical or emotional support were unrelated to measures of caregiver well-being, but greater satisfaction with emotional support provided was weakly associated with better CBI scores (Table 5).

#### 4. Discussion

PD poses a significant burden for caregivers, affecting physical, emotional and social aspects of their quality of life. Over 40% of caregivers reported that their physical health had suffered as a result of caregiving, two-thirds reported an impact on their close or distant relationships, and almost half of the caregivers had increased depression scores. This incidence of caregiver depression is comparable to that reported in Alzheimer's disease, where depression also affects approximately 50% of caregivers [29,30].

Caregiver-burden correlated with caregiver quality of life and depression scores, emphasizing the impact of caregiving on the caregivers overall health. In keeping with our results of impaired psychosocial functioning and increased psychiatric morbidity, O'Reilly et al. reported that caregivers of patients with PD had more episodes of chronic illness and higher use of tranquilizers, a five-fold increase in psychiatric morbidity, and a restricted social life compared to controls [17]. We found no difference in the degree of caregiver-burden reported by older or younger

caregivers and between genders. However, the overall age of the study sample was young, and it is therefore possible that the oldest age group was underrepresented. While female caregivers have been reported to experience greater caregiver distress than male caregivers of patients with dementia [31,32], our findings are in keeping with those by Hooker et al. [19] who found that while this was the case in Alzheimer's disease caregivers, this was not the case in PD.

The extent of caregiver-burden correlated with disease severity and increased with disability, but certain disease factors, such as hallucinations, confusion and falls, were reported as more burdensome than others, such as motor fluctuations or dyskinesias. Thus, our results confirm the findings by others who reported a significant increase of caregiver-burden with increasing disease severity [14], and by Aarsland et al. [15] who reported that mental health symptoms represent the symptoms of PD associated with the greatest impact on caregiver distress. The considerable impact of mental health problems, in particular depression, is also found in caregivers of patients with stroke and AD, but the behavioural symptoms, which have the greatest impact on caregiver-burden in AD, do not play an important role in caregiver-burden in PD [30,33–35]. In our study, self-reported motor complications of PD, particularly falls, were also associated with greater caregiver-burden, possibly reflecting the difficulty in leaving the patient unattended for a prolonged period of time due to the worry of falls. The differences in caregiver-burden scores between caregivers of patients with or without involuntary movements and motor fluctuations failed to reach significance. However, by

Table 3

The effect of symptoms of Parkinson's disease on caregiver burden and depression scores (means; SD)

	Scale of Quality of Life of Care-givers			Caregiver Burden Inventory			Caregivers' Beck Depression Inventory		
	Present	Absent	<i>p</i> -value	Present	Absent	<i>p</i> -value	Present	Absent	<i>p</i> -value
Feeling sad/depressed	109.3 (21.7)	123.9 (13.8)	<b>0.001</b>	26.0 (18.4)	14.3 (14.4)	0.003	9.9 (6.3)	6.2 (6.1)	0.005
Forgetfulness	102.5 (18.6)	121.4 (17.2)	0.007	24.6 (17.9)	16.0 (16.0)	0.16	9.5 (6.5)	6.7 (6.2)	0.08
Confusion	110.8 (20.5)	121.7 (18.1)	<b>&lt;0.0001</b>	33.2 (16.4)	16.1 (16.9)	<b>&lt;0.0001</b>	11.6 (6.0)	6.9 (6.1)	<b>0.001</b>
Hallucinations	103.6 (19.9)	119.4 (18.9)	<b>0.0005</b>	30.3 (18.2)	17.7 (16.4)	<b>0.001</b>	12.3 (6.7)	6.8 (5.7)	0.004
Falls	103.4 (20.4)	120.4 (17.8)	<b>0.0002</b>	31.3 (20.3)	15.8 (14.4)	<b>&lt;0.0001</b>	10.4 (6.5)	7.2 (6.0)	0.02
Involuntary movements	109.0 (21.4)	121.0 (21.5)	0.002	24.8 (19.2)	18.1 (17.4)	0.05	9.5 (6.5)	7.2 (6.4)	0.06
Motor fluctuations	110.1 (20.6)	120.4 (19.2)	0.008	26.3 (18.9)	15.7 (16.6)	0.002	9.9 (6.5)	6.6 (6.0)	0.01
Bladder problems	107.2 (23.3)	118.5 (18.2)	0.009	28.3 (18.8)	17.6 (16.7)	0.005	10.7 (6.3)	7.2 (6.2)	0.21
Increased sweating	114.7 (18.9)	114.7 (21.7)	1	18.9 (16.3)	23.3 (18.9)	0.3	8.2 (5.6)	8.5 (7.0)	0.8

*p*-values in bold are significant at  $p < 0.0019$  (Bonferroni-adjusted); SD, standard deviation.



Table 4

Correlations of measures of caregiver burden, quality of life and depression with patient quality of life and depression scores

Patient	Caregiver	Burden Inventory	Beck Depression Inventory
	Scale of Quality of Life of Care-givers		
PDQ-39	−0.74*	0.62*	0.38*
Beck Depression Inventory	−0.51*	0.48*	0.35*

PDQ-39, Parkinson's disease quality of life questionnaire; \* $p < 0.0125$  (Bonferroni-adjusted).

using strict Bonferroni corrections, we chose a conservative level of significance when considering the multitude of comparisons performed, increasing the possibility of a type II error and underestimating the influence of some PD symptoms. In addition, all symptoms were self-reported in this postal survey, and a more detailed assessment may have uncovered a greater impact of individual symptoms on caregiver-burden.

In addition to the impact of these disease-related factors on caregiver-burden, there was a high correlation of caregivers' burden and depression scores with patients' depression and health-related quality of life scores. A strong relationship between patient depression and quality of life scores with caregiver quality of life has been reported in Alzheimer's disease and other chronic illness [33,36], and emphasizes the interwoven relationship between patient and caregiver well-being. While a cross-sectional study like this cannot address the directionality of this relationship, this emphasizes the importance of supporting caregivers to improve patient and caregiver quality of life and to prevent nursing home placement.

Furthermore, caregiver-burden and depression scores were also related to satisfaction with the sexual and marital relationship and weakly with satisfaction with emotional support. This may reflect the strain caregiving puts on marital and social relationships or, alternatively, indicate that social factors, such as marital relationship (which may also be influenced by disease-related sexual dysfunction), play a significant role in mediating the effect of PD on the caregivers' lives. These results are in keeping with those of Edwards and Scheetz [16], who found that activities of daily living, perceived social support, psychological well-being and marital satisfaction were all significantly correlated with perceived caregiver-burden in PD. Studies in other disease groups and controls have also reported a significant relationship between QoL and marital satisfaction, and social support [37]. However, Miller et al. [3] did not find a significant association between caregiver distress and level of social support, although social contacts were significantly less than in controls. We did not assess the impact of other potentially important mediating factors such as the caregiver's family relationship to the patient (all caregivers were partners), or caregivers' coping styles and personality characteristics, all of which have been shown to influence psychosocial well-being in caregivers of patients with other chronic illnesses [37]. It is likely that these and other

personal, cultural, and social factors further contribute to caregiver-burden in PD.

#### 4.1. Limitation of this study

An important limitation of this study is that patients were not recruited through a community-based approach, but were selected as a part of a study on the impact of PD on patients and their families with particular emphasis on patients with young families. Thus, the average age of caregivers in this study was comparatively young and, while 60% of patients were older than 60 years, older patients and their caregivers were probably underrepresented. In addition, volunteers were recruited from adverts, and caregivers who experienced particular problems due to caregiver-burden may have been over-represented. However, in contrast to caregiver burden reported in chronic heart disease where younger age was associated with greater caregiverburden [38], we did not find a difference in caregiver-burden between younger and older patients within this sample, suggesting that age is not a major contributing factor to caregiver-burden in PD. The study also only analyzed the results from spouses or partners who were caregivers, which represented the vast majority of participants (97%). Thus, the results may not be generalizable to adult children as caregivers or other caregivers. The particular issues relating to children as caregivers of the parents with PD have however been addressed elsewhere [20]. Nevertheless, the study assessed a large sample of caregivers and addressed various aspects of caregiver-burden and their relationship to clinical, demographic and psychosocial parameters, thus providing greater insight into the impact of PD on caregivers of patients with PD.

We conclude that PD has a significant impact on the mental, social and physical health of caregivers. While caregiver-burden expectedly increased with longer disease duration and greater disease severity and disability, it is particularly symptoms of mental impairment, including depression, confusion, and hallucinations, as well as falls which are associated with the greatest impact on caregiver quality of life, and more attention should be paid to caregivers' emotional and physical health, particularly in advancing PD with psychiatric complications and falls. Our finding also demonstrate that patients' and caregivers' depression and quality of life scores are closely related, emphasizing the importance of viewing patient and

Table 5

Correlations of caregiver burden and depression scores with personal and social factors

	Scale of Quality of Life of Care – givers	Caregiver Burden Inventory	Caregivers' Beck depression inventory score
<i>Marital satisfaction Scale</i>			
Marital relationship	0.18	−0.42*	−0.32
Sexual relationship	0.46*	−0.50*	−0.47*
Marital discord	−0.12	0.3	0.28
Upset due to marital discord	−0.21	0.36*	0.46*
<i>Short Social Support Questionnaire</i>			
N of people providing practical support	0.26	−0.03	−0.07
Satisfaction with practical support	0.26	−0.29	−0.15
N of people providing emotional support	0.13	−0.16	−0.15
Satisfaction with emotional support	0.31	−.33*	−0.3
Beck depression Inventory score	−0.40*	0.68*	

\* $p < 0.0019$  (Bonferroni-adjusted); N = number.

caregiver as a unit. Management of caregiver distress, and its associated psychosocial aspects, should be included in the management of PD in order to improve patient and caregiver lives and to prevent nursing home placement. While only few studies on the treatment of caregiver-burden have been performed, preliminary results of intensive multi-disciplinary rehabilitation [39], but also short cognitive behavioural treatment approaches are encouraging [40], and merit further research to improve quality of life of caregivers' of patients with PD.

## References

- [1] Eagles JM, Beattie JA, Blackwood GW, Restall DB, Ashcroft GW. The mental health of elderly couples. I. The effects of a cognitively impaired spouse. *Br J Psychiatry* 1987;150:299–303.
- [2] Pearlin LI, Mullan JT, Semple SJ, Skaff MM. Caregiving and the stress process: an overview of concepts and their measures. *Gerontologist* 1990;30:583–94.
- [3] Miller E, Berrios GE, Politynska BE. Caring for someone with Parkinson's disease: Factors that contribute to distress. *Int J Geriatr Psychiatry* 1996;11:263–8.
- [4] Dickens CM, McGowan L, Percival C, Douglas J, Tomenson B, Cotter L, Heagerty A, Creed FH. Lack of a close confidant, but not depression, predicts further cardiac events after myocardial infarction. *Heart* 2004;90:518–22.
- [5] Gilhooly ML. Senile dementia: factors associated with caregivers' preference for institutional care. *Br J Med Psychol* 1986;2(Pt 2): 165–71.
- [6] Poulshock SW, Deimling GT. Families caring for elders in residence: issues in the measurement of burden. *J Gerontol* 1984;39:230–9.
- [7] Cousins R, Davies AD, Turnbull CJ, Playfer JR. Assessing caregiving distress: a conceptual analysis and a brief scale. *Br J Clin Psychol* 2002;41:387–403.
- [8] Deimling GT, Poulshock SW. The transition from family in-home care to institutional care. Focus on health and attitudinal issues as predisposing factors. *Res Aging* 1985;7:563–76.
- [9] Gilleard CJ. Influence of emotional distress among supporters on the outcome of psychogeriatric day care. *Br J Psychiatry* 1987;150: 219–23.
- [10] Goetz CG, Stebbins GT. Mortality and hallucinations in nursing home patients with advanced Parkinson's disease. *Neurology* 1995;45: 669–71.
- [11] Dura JR, Haywood-Niler E, Kiecolt-Glaser JK. Spousal caregivers of persons with Alzheimer's and Parkinson's disease dementia: a preliminary comparison. *Gerontologist* 1990;30:332–6.
- [12] Lyons KS, Stewart BJ, Archbold PG, Carter JH, Perrin NA. Pessimism and optimism as early warning signs for compromised health for caregivers of patients with Parkinson's disease. *Nurs Res* 2004;53:354–62.
- [13] Martinez-Martin P, Guerrero-Diaz MT, Frades-Payo B. Neuropsychological disorders in Parkinson's disease: evaluating them and their impact on the caregiver. *Rev Neurol* 2004;39:639–45.
- [14] Carter JH, Stewart BJ, Archbold PG, Inone I, Jaglin J, Lannon M, Rost-Ruffner E, Tennis M, McDermott MP, Amyot D, Barter R, Cornelius L, Demong C, Dobson J, Duff J, et al. Living with a person who has Parkinson's disease: the spouse's perspective by stage of disease. *Parkinson's Study Group. Mov Disord* 1998;13: 20–8.
- [15] Aarsland D, Larsen JP, Karlsen K, Lim NG, Tandberg E. Mental symptoms in Parkinson's disease are important contributors to caregiver distress. *Int J Geriatr Psychiatry* 1999;14:866–74.
- [16] Edwards NE, Scheetz PS. Predictors of burden for caregivers of patients with Parkinson's disease. *J Neurosci Nurs* 2002;34:184–90.
- [17] O'Reilly F, Finnan F, Allwright S, Smith GD, Shlomo YB. The effects of caring for a spouse with Parkinson's disease on social, psychological and physical well-being. *Br J Gen Pract* 1996;46: 507–12.
- [18] Fernandez HH, Tabamo RE, David RR, Friedman JH. Predictors of depressive symptoms among spouse caregivers in Parkinson's disease. *Mov Disord* 2001;16:1123–5.
- [19] Hooker K, Manoogian-O'Dell M, Monahan DJ, Frazier LD, Shifren K. Does type of disease matter? Gender differences among Alzheimer's and Parkinson's disease spouse caregivers *Gerontologist* 2000;40:568–73.
- [20] Schrag A, Morley D, Quinn N, Jahanshahi M. Impact of Parkinson's disease on patients' adolescent and adult children. *Parkinsonism Relat Disord* 2004;10:391–7.
- [21] Schrag A, Hovris A, Morley D, Quinn N, Jahanshahi M. Young-versus older-onset Parkinson's disease: impact of disease and psychosocial consequences. *Mov Disord* 2003;18:1250–6.
- [22] Glozman JM, Bicheva KG, Fedorova NV. Scale of Quality of Life of Care-Givers (SQLC). *J Neurol* 1998;245(Suppl 1):S39–S41.
- [23] Novak M, Guest C. Application of a multidimensional caregiver burden inventory. *Gerontologist* 1989;29:798–803.
- [24] Beck AT, Steer RA. Internal consistencies of the original and revised Beck Depression Inventory. *J Clin Psychol* 1984;40:1365–7.
- [25] Jahanshahi M, Marsden CD. Personality in torticollis: a controlled study. *Psychol Med* 1988;18:375–87.
- [26] Sarason IG. Assessing social support: the social support questionnaire. *J Pers Soc Psychol* 1983;44:127–39.

- [27] Jahanshahi M. Psychosocial factors and depression in torticollis. *J Psychosom Res* 1991;35:493–507.
- [28] Peto V, Jenkinson C, Fitzpatrick R. PDQ-39: a review of the development, validation and application of a Parkinson's disease quality of life questionnaire and its associated measures. *J Neurol* 1998;245(Suppl 1):S10–S14.
- [29] Sansoni J, Vellone E, Piras G. Anxiety and depression in community-dwelling, Italian Alzheimer's disease caregivers. *Int J Nurs Pract* 2004;10:93–100.
- [30] Rigaud AS. Epidemiology of depression in patients with Alzheimer's disease and in their caregivers. *Presse Med* 2003;32:S5–S8.
- [31] Morris RG, Woods RT, Davies KS, Morris LW. Gender differences in carers of dementia sufferers. *Br J Psychiatry Suppl* 1991;69–74.
- [32] Pruchno RA, Potashnik SL. Caregiving spouses. Physical and mental health in perspective. *J Am Geriatr Soc* 1989;37:697–705.
- [33] Teri L. Behavior and caregiver burden: behavioral problems in patients with Alzheimer disease and its association with caregiver distress. *Alzheimer Dis Assoc Disord* 1997;11(Suppl 4):S35–S8.
- [34] Rymer S, Salloway S, Norton L, Malloy P, Correia S, Monast D. Impaired awareness, behavior disturbance, and caregiver burden in Alzheimer disease. *Alzheimer Dis Assoc Disord* 2002;16:248–53.
- [35] Thommessen B, Aarsland D, Braekhus A, Oksengard AR, Engedal K, Laake K. The psychosocial burden on spouses of the elderly with stroke, dementia and Parkinson's disease. *Int J Geriatr Psychiatry* 2002;17:78–84.
- [36] Sewitch MJ, McCusker J, Dendukuri N, Yaffe MJ. Depression in frail elders: impact on family caregivers. *Int J Geriatr Psychiatry* 2004;19: 655–65.
- [37] Dunkin JJ, Anderson-Hanley C. Dementia caregiver burden: a review of the literature and guidelines for assessment and intervention. *Neurology* 1998;51:S53–S60.
- [38] Dracup K, Evangelista LS, Doering L, Tullman D, Moser DK, Hamilton M. Emotional well-being in spouses of patients with advanced heart failure. *Heart Lung* 2004;33:354–61.
- [39] Trend P, Kaye J, Gage H, Owen C, Wade D. Short-term effectiveness of intensive multidisciplinary rehabilitation for people with Parkinson's disease and their carers. *Clin Rehabil* 2002;16: 717–25.
- [40] Brown RG, Secker DL. A randomized controlled trial of cognitive Behavioral Therapy (CBT) for carers of patients with Parkinson's disease. *Mov Disord* 2004;19(suppl 9):P734.