





Caring for a loved one with Parkinson's disease: the role of coping styles and relationship quality

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ABSTRACT

Objective: Informal carers play an essential role in the care of individuals with Parkinson's disease (PD). This role, however, is often fraught with difficulties, including emotional, physical, and financial. Coping styles and relationship quality have been hypothesized to influence the impact of stressors. The aim of this study is to examine the relationship between carers' coping style, relationship quality, and carer burden.

Design: Cross-sectional.

Participants: Thirty-nine PD patient carer dyads were included in the study.

Measurements: Participants completed self-rated questionnaires including the Dyadic Adjustment Scale, Zarit Burden Interview, and Brief Coping Orientation to Problems Experienced Inventory.

Results: Correlational analyses found significant and positive correlation between carer burden and all three coping styles (problem-focused, emotion-focused, and dysfunctional). There was also a moderate association between carers' perceived relationship quality and satisfaction and carer burden. Regression analyses found that carer's gender, severity of PD, relationship quality, emotion-focused, and dysfunctional coping styles did not predict carer burden. Conversely, problem-focused coping style predicted carer burden.

Conclusion: The results highlight that there is no perfect way to react and care for a loved one and serves as important information for practitioners who design and implement interventions.

Key words Parkinson's disease, carers, quality of life

Introduction

In 2014, it was estimated that Australia had 10,150 Parkinson's disease (PD) carers and 15.3% of them were of working age (Deloitte Access Economics, 2015). The responsibility of caring is often assumed by spouses. Due to the chronicity of the disease, the caregiving role usually unfolds slowly over a long period of time (Dyck, 2009). The unpredictable nature of PD can further add to the complexity of providing care. Depending on the needs of the PD

patient, type of care can vary. While the provision of support with activities of daily living are fairly easy to measure because they can be counted, less obvious activities, such as emotional support and companionship, are equally important and should not go unnoticed.

Caring for one with PD can come at a significant cost to the carer, otherwise known as carer burden, defined as "the extent to which caregivers perceive that caregiving has had an adverse effect on their emotional, social, financial, physical and spiritual functioning" (Zarit *et al.*, 1986). Within the PD population, there have been numerous studies indicating that providing care for PD patients can be stressful and burdensome (Martinez-Martín *et al.*, 2007; McRae *et al.*, 1999; Williamson *et al.*, 2008). This stress can in turn have consequences on the well-being of the patient as carer fatigue and ill

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health can negatively impact the quality of care provided.

While patient factors have been reported to influence carer burden, carer factors are also important to consider when investigating carer burden and carer's quality of life. Coping strategies have been hypothesised to be mediators of the impact of stressors on health outcomes and have been investigated in other chronic illnesses such as severe head injuries and epilepsy (Andel *et al.*, 2011; Sander *et al.*, 1997). The term "coping" refers to behavioral and cognitive efforts in managing demands that are considered challenging or exceeding the capacity of the person (Lazarus and Folkman, 1984). Coping styles can be categorized into three broad groups: emotion-focused, problem-focused, and dysfunctional. The most constructive coping response will differ based on the nature of the stressor.

Another factor worthy of consideration when thinking about carer burden is the relationship quality. There is some evidence that spouses experience negative relationship changes as a consequence of illness. In chronic illnesses such as dementia, advanced cancer, and psychiatric conditions, there is evidence that spousal caregiving places an enormous strain on the quality of marital relationships (Ascher *et al.*, 2010; Quinn *et al.*, 2009; Spruytte *et al.*, 2002; Zhou *et al.*, 2011). The perceived quality of marital relationships in turn can lead to different caregiving experiences. Carers who perceive their relationship with the care recipient as positive and supportive report less care burden and fewer depressive symptoms (Schumacher *et al.*, 2007). In contrast, poor quality care relationships engender more depressive symptoms and a greater sense of care burden for informal carers (Braun *et al.*, 2009).

While a number of studies have investigated the relationship between coping styles and the caregiving experience in chronic illnesses, the research within PD is limited. To the authors' knowledge, there have only been two papers published thus far. Sanders-Dewey *et al.* (2001) studied 44 PD patient-carer dyads and found that emotion-focused coping and perceived uncertainty about the illness emerged as significant predictors of carer distress. They utilized the Revised Ways of Coping Checklist (WOCL) as a measure to determine specific coping strategies in response to a recent life stressor. While eight distinct subscales can be derived from the WOCL, the authors chose a two-factor approach, investigating emotion-focused and problem-focused strategies. However, it has been suggested that emotion-focused strategies can be both helpful and unhelpful, and the amalgamation of them into a single factor may be problematic (Carver *et al.*, 1989). Another study by Hobson *et al.* (2001) recruited 79 PD patient-carer dyads. The study

investigated the relationship between coping styles and depression in carers and found that avoidance coping was associated with depression. In contrast, those who employed more cognitive coping methods were less depressed.

Furthermore, relatively little attention has been given to the caregiving context and the quality of the dyadic relationship. To date, the only paper evaluating the relationship quality and satisfaction in PD patient-carer dyads was published by Ricciardi *et al.* (2015). Fifteen dyads completed several measures assessing relationship quality and satisfaction, alexithymia, and empathy, as well as depressive and anxious symptoms. A significant negative correlation was found between alexithymia and relationship satisfaction in PD individuals. However, patient's and carer's rating of their relationship did not appear to be influenced by mood indicators (anxiety and depression), disease-related factors, or relationship characteristics. Unfortunately, the small sample size is a limitation and the study also failed to include a measure of carer burden, which is arguably an important component and a more holistic measure of the caregiving experience.

Thus, the purpose of the present study is three-fold. First, we sought to understand the relationship between different coping styles and carer burden. Second, we examined the relationship between perceived relationship quality and carer burden. Finally, we looked at the contribution of the various coping styles, relationship quality, carer's gender, and severity of PD in the prediction of carer burden. Gender was included as a variable as previous research found that female carers tended to employ more avoidance strategies as compared to male carers (Ashley and Kleinpeter, 2002).

Methods

Participants and procedure

This study was conducted in accordance with approval from The University of Queensland's and Royal Brisbane and Women's Hospital Human Research Ethics Committees. Patient-carer dyads were recruited from neurology outpatient clinics and advertisements. Patients had a confirmed diagnosis of PD according to the United Kingdom Brain Bank criteria by neurologists (Hughes *et al.*, 1992). They were included in the current study if they had a carer who was also willing to participate in the study. Participants with a diagnosis of mild cognitive impairment were not excluded from the analyses, while those with a formal diagnosis of dementia made by a neurologist were excluded. They were also excluded if they had a diagnosis of another neurological condition.

Patients who were referred by their neurologist were contacted via phone or email. Ninety-two patients were contacted. Of which, 42 had carers who were willing to participate in the study. This current research sample only consisted of spouse carers.

Once they had consented to participate in the study, a study package containing questionnaires was mailed out to them. A separate study package was sent to the carer. Patients also attended two face-to-face interview sessions during which cognitive and psychological assessments were administered. Completed questionnaires were collected from patients when they presented for the first interview session.

Measures

Patients assessments comprised of the Montreal Cognitive Assessment (MoCA), and Hoehn and Yahr Staging completed by an experienced research assistant, and the Dyadic Adjustment Scale (DAS) completed by the patients. In addition to the DAS, carers also completed the Zarit Burden Interview (ZBI) and Brief Coping Orientation to Problems Experienced (Brief COPE) scale.

MONTREAL COGNITIVE ASSESSMENT

The MoCA is a cognitive screening tool that has been validated for the detection of mild cognitive impairment or dementia in PD patients (Hoops *et al.*, 2009; Nasreddine *et al.*, 2005). A score of 26/27 has been suggested as an optimal cutoff score (Hoops *et al.*, 2009). **Hoehn and Yahr.** The Hoehn and Yahr (H&Y) is the first rating scale to describe the progression of PD and the level of associated disability (Hoehn and Yahr, 1967). It has five stages (stage one: mildest to stage five: most advanced).

DYADIC ADJUSTMENT SCALE

The DAS is one of the most widely cited measures of relationship adjustment (Spanier, 1979). It is a 32-item scale that ranges from 0 to 151, with higher scores indicating better dyadic adjustment. It can be used for either married or unmarried cohabiting couples. It yields four factors: dyadic satisfaction, dyadic consensus, dyadic cohesion, and affectional expression. Dyadic satisfaction (10 items) refers to the degree to which the couple is satisfied with the relationship. Dyadic consensus (13 items) is the extent to which the couple agrees on matters of importance to the relationship (e.g. finances, friendships). Dyadic cohesion (five items) refers to the sharing of pleasant activities by the couple, and affective expression (four items) reflects the degree of demonstrations of affections and sexual relations. Typically, cutoff scores between 92 and 107 are used

to differentiate between distressed and non-distressed couples (Sabourin *et al.*, 2005).

ZARIT BURDEN INTERVIEW

The ZBI is a popular measure of carer burden. It contains 22 items and each item is rated on a 5-point scale (Zarit *et al.*, 1980). Response options range from 0 (Never) to 4 (Nearly Always), resulting in a range between 0 and 88 with higher scores indicating increased burden. A study by Hagell *et al.* (2017) provided initial support for the reliability and validity of the ZBI for use with PD carers.

BRIEF COPING ORIENTATION TO PROBLEMS EXPERIENCED SCALE

The Brief COPE scale is a 28-item self-completed questionnaire measuring coping strategies (Carver, 1997). It consists of 14 subscales and research with carers of Alzheimer's disease patients derived three composite subscales that have proven useful in clinical research: emotion-focused, problem-focused, and dysfunctional coping (Cooper *et al.*, 2008a). Carers were asked to score each item from 1 (not doing it at all) to 4 (doing it a lot). Scores in the three composite subscales were summed and the score range for emotion-focused coping was 10–40; problem-focused coping was 6–24 and dysfunctional coping was 12–48.

DATA ANALYSIS

Statistical analysis was performed using Statistical Package for Social Science version 26, and associations between the variables were evaluated with bivariate correlational analyses (Spearman's correlation). Correlations were interpreted as per Cohen (1988) recommendation: $r = 0.10$ – 0.29 (small), $r = 0.30$ – 0.49 (medium), and $r = 0.50$ – 1.0 (large). All assumptions and hypotheses were tested using a 5% level of significance.

Three separate multiple regression analyses were then carried out with carer burden as the dependent variable. Independent variables were relationship quality, carer's gender, and severity of PD. One of the three coping style was also included in each of the models as an independent variable. All analyses, including follow-up comparisons, were hypothesis-driven and planned a priori. No family-wise error corrections were applied, and the alpha level used for all tests was 0.05 (Howell, 2013; Saville, 1990).

Prior to analysis, basic data checks were performed. There were two PD patients who had incomplete data on the DAS and were thus excluded from the analyses. Scores were considered outliers at 3.29 SD from the mean. The data of one particular patient-carer dyad consistently had outliers across most measures and hence, excluded from

subsequent analyses. One outlier was identified within the DAS (patient) and DAS (carer). Performing the analyses with and without these outliers produced similar results and were thus retained in the analyses. After excluding three dyads, data from 39 dyads were analyzed.

Assumptions for multiple regression were also checked and met. Based on Miller and Kunce (1973) recommendation of 10 subjects per variable, a maximum of 4 variables were included in each model. The dependent variable was measured on a continuous scale and independent variables were either continuous or categorical.

Results

Demographic, cognitive, and motor variables

As stated above, a total of 39 patient–carer dyads were included in data analysis. Table 1 outlines the demographic, cognitive, and motor variables for PD patients and their carers. The mean age of patients and carers was 67.9 and 67.1 years, respectively. The majority of the carers were female (61.5%), and the majority of the patients were in the mild stages of the disease (Stage 1 and 2 of the H&Y: 89.7%).

Self-report measures

Table 2 presents a summary of patients' and carers' responses on mood and relationship satisfaction questionnaires.

Correlational analyses

There was a positive and significant correlation between carer burden and emotion-focused coping ($r = 0.41, p = 0.01$); problem-focused coping ($r = 0.58, p < 0.001$), and dysfunctional coping ($r = 0.52, p < 0.01$).

There was a significant, negative correlation between carer burden and self-reported levels of relationship adjustment, and satisfaction (DAS-total: $r = -0.36, p = 0.03$). Table 3 provides the full results and break down of the carers' DAS subscales.

Regression analyses

Table 4 outlines the results from the three regression models. The first model was conducted to investigate whether dyadic adjustment, severity of PD, gender, and problem-focused coping would significantly predict carer burden. The results indicated that the model explained 31.7% of the variance [$F(4,34) = 3.94, p = 0.01$]. The use of problem-focused coping strategies was the only independent variable that contributed significantly to the model ($\beta = 0.39, p = 0.02$).

Table 1. Descriptive statistics of demographic, cognitive, and motor variables

CHARACTERISTICS	PD PATIENTS (N = 39)	CARERS (N = 39)
Age		
Mean (SD)	67.9 (8.4)	67.1 (8.3)
Range	48–86	49–80
Gender		
Male, N (%)	24 (61.5)	15 (38.5)
Female, N (%)	15 (38.5)	24 (61.5)
Years of education, Mean (SD)	13.2 (3.4)	–
Years of relationship, Mean (SD)	41.5 (15.0)	41.5 (15.0)
MoCA, Mean (SD)	25.0 (3.5)	–
H&Y		
Mean (SD)	1.5 (0.7)	–
Stage 1, N (%)	22 (56.4)	–
Stage 2, N (%)	13 (33.3)	–
Stage 3, N (%)	4 (10.3)	–
Stage 4, N (%)	0 (0%)	–

Table 2. Descriptive statistics for self-report measures

MEASURES	PD PATIENTS (N = 39)	CARERS (N = 39)
DAS – Total, Mean (SD)	115.6 (15.0)	119.1 (18.3)
DAS – Dyadic Consensus, Mean (SD)	51.3 (6.8)	52.8 (7.8)
DAS – Dyadic Cohesion, Mean (SD)	16.3 (3.7)	17.0 (4.6)
DAS – Dyadic Satisfaction, Mean (SD)	39.4 (6.9)	40.7 (6.8)
DAS – Affectional Expres- sion, Mean (SD)	8.6 (2.6)	8.6 (3.0)
COPE – Emotion-focused	–	18.9 (5.9)
COPE – Problem-focused	–	11.0 (4.0)
COPE – Dysfunctional	–	15.8 (4.4)
ZBI, Mean (SD)	–	12.7 (10.2)

The second multiple regression model with carer burden as the dependent variable and carer DAS (total), COPE (emotion-focused), disease severity, and carer gender as independent variables produced a $R^2 = 0.23$ [$F(4,34) = 2.55, p = 0.06$]. None of the four independent variables contributed significantly to the model.

Finally, the last model was conducted to investigate whether dyadic adjustment, severity of PD, gender, and dysfunctional coping style could significantly predict carer burden. The results indicated that the model explained 25.2% of the variance and was significant [$F(4,34) = 2.86, p = 0.04$]. However,

Table 3. Spearman's Rho correlations between measures of relationship satisfaction, anxiety, and carer burden in carers

CARER FACTOR	DAS-TOTAL	DYADIC CONSENSUS	DYADIC COHESION	DYADIC SATISFACTION	AFFECTIONAL EXPRESSION
ZBI	-0.36*	-0.37*	-0.26	-0.27	-0.25

* $p < 0.05$.**Table 4.** Factors associated with carer burden

VARIABLES	B	SE B	B	T	P
<i>Model 1 (R² = 0.32, p = 0.01*)</i>					
COPE (Problem-focused)	0.99	0.42	0.39	2.39	0.02*
DAS (Total)	-0.08	0.09	-0.14	-0.87	0.39
H&Y	3.07	2.23	0.21	1.38	0.18
Gender	0.62	3.16	0.03	0.20	0.85
<i>Model 2 (R² = 0.23, p = 0.06)</i>					
COPE (Emotion-focused)	0.34	0.30	0.20	1.12	0.27
DAS (Total)	-0.12	0.09	-0.21	-1.23	0.23
H&Y	3.42	2.37	0.23	1.44	0.16
Gender	1.54	3.33	0.08	0.46	0.65
<i>Model 3 (R² = 0.25, p = 0.04*)</i>					
COPE (Dysfunctional)	0.57	0.38	0.25	1.49	0.15
DAS (Total)	-0.10	0.09	-0.17	-1.01	0.32
H&Y	3.88	2.31	0.26	1.68	0.10
Gender	2.23	3.23	0.11	0.69	0.49

none of the predictors were significantly independent predictors of carer burden.

Discussion

The present study sought to better understand the following: (1) the relationship between carer burden and the coping strategies of carers; (2) the relationship between carer's perceived quality of relationship and carer burden, and (3) whether different coping styles, relationship quality, gender, and severity of PD predict carer burden.

First, findings from the correlational analyses found a significant and positive correlation between carer burden and all three coping styles (problem-focused, emotion-focused, and dysfunctional). Specifically, higher carer burden was associated with increased use of problem-focused, emotion-focused, and dysfunctional coping strategies. At the bivariate level, there was a moderate correlation between carer burden and emotion-focused coping styles, while the strength of the relationship between the other two coping styles and carer burden was considered large. These findings are mostly in keeping with the current caregiving literature (Lavarone *et al.*, 2014; Sanders-Dewey *et al.*, 2001). However,

a particularly striking result that differed from previous studies was the relationship between problem-focused coping style and carer burden, in which the two variables were not only correlated but problem-focused coping style was predictive of carer burden. Most of the previous studies in other chronic illness populations have indicated that an increased use of problem-solving strategies is related to lower psychological distress and carer burden (Haley *et al.*, 1987). A possible explanation may relate to the concept of locus of control, in which having control over or an active manipulation of the environment or situation does not necessarily lead to a reduction in the negative effects of the stressful situation. In the context of providing care to PD patients where the symptoms became progressively worse, many carers may attempt to control the situation through problem-focused coping strategies such as reading and researching about the condition or putting in safety mechanisms in the home. While these strategies allow the carer to be actively involved in maintaining control, it does not necessarily reduce the demands and rigours of the caregiving role. Furthermore, problem-focused strategies concentrates on tackling the present issues and hence, may not be helpful in addressing feelings of grief and loss experienced by these carers.

The second important finding of this study was a moderate association between carers' perceived relationship quality and satisfaction. On closer inspection of the subscales, this relationship was mainly driven by the dyadic consensus factor which is a measure of the degree of harmonious accord between partners on matters of importance in the relationship. Examples of these matters may include finances, religion, and conventionality (correct or proper behavior). It is undeniable that all close relationships experience conflict to some degree. However, frequent conflict in a strongly interdependent relationship such as a patient–carer one can dominate the relationship to the exclusion of everything else (Peterson, 1983). Poor relationship consensus may be explained by the equity theory, which essentially posits that there should be a balance between giving and receiving in every relationship (Walster *et al.*, 1978). As the symptoms of PD worsen, the dyad is likely to experience an inequity because of the imbalance on care provision and receiving. For carers, providing care may be a new and unexpected role that they are asked to do. Additionally, patients may also struggle with their dependence on others. This imbalance between give and take is often associated with carer burden and poor psychological well-being (Snyder, 2000; Williamson and Shaffer, 2001). Thus, marital therapy to support the couple navigate some of these new challenges may be of benefit (Spencer and Haub, 2018).

Our multivariate regression analyses found that carers' gender, severity of PD, and relationship quality did not predict carer burden; however, these negative results should be interpreted with caution due to limitations with sample size for regression analysis and low power when interpreting results. Barusch and Spaid (1989) previously reported that carer's gender was a significant predictor of carer burden once age had been taken into consideration. They found that younger carers were more likely to experience higher levels of carer burden. In this current sample, 23 (59%) of the carers were aged 65 years and above, which may explain why gender did not predict carer burden in this study. Additionally, other constructs such as resilience could modulate this association (Lundman *et al.*, 2007). The sample did not include any patients who were in the severe stage of PD, likely due to the challenges with attending face-to-face sessions when managing significant motor symptoms. It is conceivable that carers who are experiencing a high level of stress may be unsatisfied with the relationship.

To the authors' best knowledge, this is the first study to investigate the links between relationship quality, carer burden, and coping styles in the PD carer cohort. It is also the first study in this

population to measure coping styles in a comprehensive manner, considering all three different types.

In this study, we did not adjust the threshold for adjusting for multiple comparisons; therefore, Type 1 errors can be possible and is a limitation. It is also important to note that this study is cross-sectional in design and the findings were based on data collected at one time point. Hence, they do not lend themselves to directly assessing cause and effect relationships. Recent evidence has drawn attention to the clinical importance of assessing carers over time and longitudinal studies will certainly be beneficial in understanding if there are any changes in coping styles or relationship quality as the disease progresses (Cooper *et al.*, 2008b). Data on coping styles were obtained through self-reports. It is not entirely clear if the findings would be different if actual observations of carer coping behaviour were used. A combination of methods is likely to be the most ideal.

The premorbid nature of the relationship could have had further consideration in this study. There is evidence that premorbid relationship satisfaction is related to carer burden, in which less satisfaction may negatively affect carer's reactions to patient's behaviors, communication, and problem-solving skills. It was found that this relationship persisted after controlling for disease severity, impairment in activities of daily living, and frequency of cognitive impairment (Lea Steadman *et al.*, 2007). Factoring this in may provide further clarification of the relationship between relationship adjustment and carer burden.

Overall, the results from this study underscores the importance of conducting a thorough and holistic assessment of specific caregiving duties, current circumstances, and personality factors before providing any recommendations, rather than approaching it in a "one-size-fits-all" manner. Interventions that aim to improve harmonious accord between dyads are also likely to enhance carer's perceived relationship quality and reduce caregiver strain in PD.

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Conflict of interest

None.

Description of authors' roles

A. Zhang – study design, statistical analysis, and writing of the manuscript. J. Yang – data collection. T. Au – data collection and data management assist. G. Byrne – financial support, and reviewed and critiqued the manuscript. J. O'Sullivan – participant recruitment, and reviewed and critiqued the manuscript. N. Pachana – reviewed and critiqued the manuscript. L. Mitchell – reviewed and critiqued the manuscript. N. Dissanayaka – study design, supervised the data collection and analysis of the results, and reviewed and critiqued the manuscript.

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