



King's Research Portal

DOI:

[10.1155/2017/4697052](https://doi.org/10.1155/2017/4697052)

Document Version

Publisher's PDF, also known as Version of record

[Link to publication record in King's Research Portal](#)

Citation for published version (APA):

Karlstedt, M., Fereshtehnejad, S. M., Aarsland, D., & Lökk, J. (2017). Determinants of Dyadic Relationship and Its Psychosocial Impact in Patients with Parkinson's Disease and Their Spouses. *Parkinson's disease*, 2017, Article 4697052. <https://doi.org/10.1155/2017/4697052>

Citing this paper

Please note that where the full-text provided on King's Research Portal is the Author Accepted Manuscript or Post-Print version this may differ from the final Published version. If citing, it is advised that you check and use the publisher's definitive version for pagination, volume/issue, and date of publication details. And where the final published version is provided on the Research Portal, if citing you are again advised to check the publisher's website for any subsequent corrections.

General rights

Copyright and moral rights for the publications made accessible in the Research Portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognize and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from the Research Portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying the publication in the Research Portal

Take down policy

If you believe that this document breaches copyright please contact librarypure@kcl.ac.uk providing details, and we will remove access to the work immediately and investigate your claim.

Research Article

Determinants of Dyadic Relationship and Its Psychosocial Impact in Patients with Parkinson's Disease and Their Spouses

Michaela Karlstedt,¹ Seyed-Mohammad Fereshtehnejad,^{1,2} Dag Aarsland,³ and Johan Lökk¹

¹Karolinska Institutet, Department of Neurobiology, Care Sciences and Society, Division of Clinical Geriatrics, Novum Pl 5, Blickagången 6/Hälsövägen 7, 14157 Huddinge, Sweden

²Department of Neurology and Neurosurgery, McGill University, Montreal, QC, Canada

³Karolinska Institutet, Department of Neurobiology, Care Sciences and Society, Division of Neurogeriatrics, Novum Pl 5, Blickagången 6/Hälsövägen 7, 14157 Huddinge, Sweden

Correspondence should be addressed to Michaela Karlstedt; michaela.karlstedt@ki.se

Received 18 November 2016; Revised 8 January 2017; Accepted 17 January 2017; Published 14 February 2017

Academic Editor: Hélio Teive

Copyright © 2017 Michaela Karlstedt et al. This is an open access article distributed under the Creative Commons Attribution License, which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited.

The caregiver-care receiver relationship (mutuality) in Parkinson's disease (PD) and its association with motor and non-motors symptoms, health-related quality of life (HRQoL), and caregiver burden have not fully been investigated. The aim of our study was to explore if (1) the level of mutuality perceived by PD-patients and PD-partners differs, (2) different factors are associated with perceived mutuality by PD-patients and PD-partners, and (3) mutuality is associated with PD-patients health-related quality of life (HRQoL) and caregiver burden. We collected data on motor signs (UPDRS III), non-motor manifestations (NMSQuest), PD-patients' cognition (IQCODE), mutuality scale (MS), PD-patients' HRQoL (PDQ8), and caregiver burden (CB) from 51 PD dyads. Predictors were identified using multivariate regression analyses. Overall, the dyads rated their own mutuality as high with no significant difference between the dyads except for the dimension of reciprocity. PD-patients' MS score ($p = .001$) and NMSQuest ($p \leq .001$) were significant predictors of PDQ8. Strongest predictor of CB was PD-partners' MS score ($<.001$) and IQCODE ($p = .050$). In general, it seems that non-motor symptoms contribute to a larger extent to the mutual relationship in PD-affected dyads than motor disabilities.

1. Introduction

Parkinson's disease (PD) is a complex neurodegenerative disorder resulting in a combination of motor impairment and a wide range of non-motor manifestations. Non-motor symptoms (NMS) can emerge from nearly all organ systems, such as neuropsychiatric, gastrointestinal, urogenital, and other autonomic presentations partly due to extrastriatal brain changes [1].

A body of evidence suggests that PD as a progressive disabling condition may lead to not only lack of autonomy due to increasing dependency but also placing an increased burden on caregivers and consequently has an impact on the care dyads' health-related quality of life (HRQoL) [1–5]. The construct of HRQoL is complex but can be defined as the “perception and self-evaluation regarding the impact of the

disease and its consequences on his/her life in the terms of physical, psychological and social aspects” [4, 6].

Not all family members may regard themselves as caregivers, especially when symptoms are less severe in the early stage of PD. However, the inevitable course of the disease may result in functional dependency and need of help in order to perform daily activities. This can transform the quotidian caregiving activities and lead to emotional, social, and economic strain [7, 8].

An important aspect of caregiving situation is the relationship between the caregiver and care receiver. Research has demonstrated that the quality of relationship can affect caregiver outcomes [9, 10]. Mutuality, defined by Archbold and colleges as the positive quality of relationship, is now widely used to signify relationship quality [10–12]. Mutuality has four dimensions: love and affection, shared pleasurable

activities, shared values, and reciprocity [11, 12]. A review suggests that high mutuality can be an important protective factor against caregiver burden in progressive conditions such as PD [10]. Conversely, low mutuality can be a risk factor for increased caregiving burden and depression for the caregivers. So far, the effect of mutuality has mainly been explored in PD caregiver samples [9, 13, 14]. Very few studies have explored mutuality from the perspective of the PD-patients and their partners and these studies have mainly been based on small sample sizes. Nonetheless, their result has suggested that perceived dyadic benefits of living with PD are associated with greater marital quality and that mutuality may act as mediator of PD-patients HRQoL [15, 16]. In contrast to studies with frail elderly and stroke patients [17, 18] Ricciardi et al. found PD-patients to be less satisfied with relationship than their partner. Furthermore, they did not find any association between mutuality and PD motor impairment or disease duration [19]. More research is needed particularly on the relationship of mutuality and motor and NMS.

Therefore, the aim of this study was to identify factors associated with mutuality, HRQoL, and caregiver burden. We used the modified stress-appraisal model proposed by Greenwell et al. (2015) to guide us in our analytic plan [9, 20]. The model suggests that primary stressors (e.g., disease-related factors) and the individuals' appraisal of the situation (e.g., carer involvement, coping strategies) have direct and indirect effects via protective factors such as mutuality on caregiver burden and HRQoL. Mutuality is also proposed to have a direct effect on caregiver burden and HRQoL. In the present study we only explored primary stressors association with mutuality and outcomes such as PD-patients HRQoL and caregiver burden. We hypothesized that there are (1) differences of perceived level of mutuality by PD-patients and PD-partners, (2) differences in factors associated with the mutuality of PD-patients and PD-partners, and (3) a relationship between mutuality perceived by PD-patients and PD-partners as well as PD-patients' HRQoL and caregiver burden.

2. Materials and Method

2.1. Participants. In the present study, we report results from baseline data of a longitudinal study. Fifty-one PD dyads were recruited during 2014-2015, from the movement disorders clinics at Karolinska University Hospital ($n = 42$), Sweden, and through advertisement in the journal of the Swedish Parkinson's Disease Association ($n = 9$). The study was approved by the local research ethics committee (registration number: 2013/1812-31/3) and was conducted in accordance with the declaration of Helsinki.

2.2. Eligibility Criteria. To be included in the study, a specialist in movement disorders should have diagnosed the PD-patient. They should be living together as partners (≥ 3 years), aged ≥ 55 , but should not be in the phase of parenting small children. Furthermore, none of the PD-partners should be employed as a caregiver. Other eligibility criteria consisted of acceptable cognition based on Montreal Cognitive

Assessment (MoCA, [score ≥ 23]) and no severe medical conditions other than PD affecting daily life, which was judged by MK.

2.3. Procedure. The clinical examinations were performed by MK. The care dyads filled out the questionnaires' separately and individually, in the presence of the first author, at the outpatient clinic or during a home visit whichever was most convenient for the dyads. The questionnaires were filled out after having obtained, read, and signed a written consent. Descriptive and sociodemographic data was also collected.

2.4. Measurements

2.4.1. Dependent Variables. PD-specific HRQoL was measured with the Parkinson's Disease Questionnaire-Short Form (PDQ8). The scale comprises 8 items, using 5-point Likert scale, and covers domains as mobility, activities of daily life, emotional wellbeing, stigma, social support, cognition, communication, and bodily discomfort. A summary index (PDQ8SI) was calculated as the sum of items divided by maximum per item times number of items and then multiplied by 100. Higher scores, ranging from 0 to 100% indicate worse quality of life [21].

The caregiver's burden scale (CBS) was used to measure the PD-partners' reaction to caregiving. The scale contains 22 items and is answered using a 4-point Likert scale (1 = not at all to 4 = often). It covers domains such as general strain, isolation, disappointment, and emotional involvement. The total scale score ranges from 22 to 88. Higher score indicates more feelings of stress and burden in the caregiving situation [22]. The CBS has been used in samples of patients with Parkinson's disease and other neurological disorders [22–24].

2.4.2. Dependent and Predictor Variable. The quality of the caregiver-care receiver relationship was measured through the mutuality scale (MS) [11, 12]. The scale contains 15 items, where each item is answered using a 5-point Likert scale (0 = not at all to 4 = a great deal). It covers domains such as love and affection (3 items), shared pleasurable activities (4 items), shared values (2 items), and reciprocity (6 items) [12, 18]. The summary score is calculated as the mean value of all the individual items' scores for the whole scale and the above-mentioned domains. The total scale score ranges from 0 to 4. Higher scores indicate better quality of mutual relationship between the care dyads [11, 12]. We have recently reported the psychometric properties of the Swedish version of MS [25].

2.4.3. Predictor Variables. We used the Hoehn and Yahr (H/Y) scale to determine stage of PD. It contains 6 stages where 0 indicates no visible symptoms and 5 represents a PD-patient who is unable to walk unless assisted [26].

The Unified Parkinson's Disease Rating Scale-Part III (UPDRS III) was used to evaluate severity of PD-specific motor signs. The scale contains 14 items and is answered using a 5-point Likert scale. Higher scores indicate more severe motor signs [27].

The Non-motor Symptom Questionnaire (NMSQuest) was used to detect PD-specific non-motor manifestations in

domains such as gastrointestinal, urinary, sexual function, cardiovascular, attention/memory, hallucination, depression/anxiety, sleep/fatigue, and miscellaneous. The scale contains 30 items scored "yes" or "no." Higher score indicates higher frequency of non-motor manifestations [28].

Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE) uses information from the caregiver to assess functional changes associated with cognitive functioning in the patients under care. The scale contains 26 items and is answered using a 5-point Likert scale. The individual score is calculated by the mean across all item scores, ranging between 1 and 5. Higher score (>3) indicates decline in cognitive functioning [29].

The PD-patients' physical functioning and level of dependency were assessed by the PD-partner using the modified form of the extended Katz index [30]. The scale comprises items assessing grooming/dressing, bathing, food intake, toileting, walking/transferring, housekeeping, and shopping. The scale is answered using a 4-point Likert scale (0 = no help to 3 = need all help). A dichotomous variable (0 = independent and 1 = dependent) was created aiming to assess dependency.

We also created a pooled dichotomous variable of the level of education of the PD-patient and the PD-partner (0 = either elementary, secondary, or only one with university education, 1 = both with university education).

2.4.4. Montreal Cognitive Assessment (MoCA). To assess cognitive functioning, the MoCA screening instrument was used. Scores above 26 are considered to be normal [31].

2.5. Statistical Analysis. Continuous and discrete numerical variables are described using mean and standard deviation (SD), whereas stages of PD assessed by H/Y are presented as the median and interquartile range (IQR). Nominal and categorical data are reported as relative frequency and percentages. Prior to the main analyses, we explored the normality of the distribution of all the dependent variables (DVs). Most of the dependent variables' total score were normally distributed with no excessive skewness or kurtosis. Spearman correlation coefficient was calculated to assess direction and magnitude of the correlation between potential predictors and the DVs. Correlation coefficients between 0.1 and 0.29 were considered as weak, 0.3 and 0.49 as medium, and >0.5 as strong [32]. Predictors with correlation coefficients > 0.1 were entered into the multivariate regression models. Our a priori hypotheses on the relationship between the included variables were guided by the aim of the study and the stress-appraisal model [20]. This means that disease-related factors, PD-patients, and PD-partners mutuality may be potential predictors of PD-patients' HRQoL and caregiver burden. Furthermore, disease-related factors may also predict mutuality.

Separate regression analyses were performed for each group and for each dependent variable; that is, we performed one regression analysis including predictors of PD-patients' MS and one including predictors of PD-patients' HRQoL. Furthermore, one regression analysis was performed with predictors of PD-partners' MS and one including predictors of caregiver burden. PD-partners' gender, age, and education

were used for statistical adjustments. Assumptions of linearity, normality, and homoscedasticity were examined through histogram and scatterplots of residuals (Table 5). No influential multivariate outliers were detected using Mahalanobis and Cook's distance (<1) [33]. The Mann-Whitney *U* test was used to test the differences of MS total scores and the dimension scores between PD-patients and PD-partners. Prior to data collection, sample size was calculated based on available data from previous studies reporting differences in MS scores between caregivers and care receivers [13, 17]. To detect a standardized difference of 0.63 between PD-patients and PD-partners, with a power of 80% and a two-sided significance level of 0.05, a total of 40 subjects in each group is required. To take into account possible drop-outs due to the longitudinal design of the project, 51 dyads were recruited. All data analyses were conducted using IBM SPSS Statistics for Windows, version 23 (IBM Corp., Armonk, NY, USA).

3. Results

3.1. Missing Data. Two single missing items by two subjects within the NMSQuest scale were identified. These study subjects had individual scores larger than the samples median. To avoid case-wise deletion and loss of power, these missing values were imputed with a zero score.

3.2. Baseline Characteristics. Mean age for the PD-patients was 70.9 (SD = 8.5) and 70.7 (SD = 9.3) years for the partners. Mean length of cohabitation was 38.4 (SD = 14.5) years. Other sociodemographic and clinical features are presented in Table 1. The most frequent reported NMS was nocturia (78.4%) and urgency (74.5%) (Table 2). Of the PD-patients 35/51 (68.6%) needed some form of supervision or help in daily activities. When help was needed the PD-partner was the main provider of that help. Instrumental activities such as shopping (32/51) or cooking/cleaning (28/51) were the most frequent tasks requiring help from the PD-partners (Table 3). Two PD-patients out of 51 (4%) were unable to be left alone in the home and 33% (17/51) could be alone between 2 and 12 hours. The remaining 63% (32/51) were able to be alone unlimited time.

3.3. Dyadic Differences in Total MS Score and Dimension Score. There was no significant difference between the total scores of the MS in PD-patients (median = 3.4) and PD-partners (median = 3.1). Regarding dimensions of the MS, only reciprocity (median = 3.3 versus median = 2.8, $p = .014$) was significantly higher rated by PD-patients (Table 1).

3.4. Bivariate Correlations. Table 4 summaries bivariate correlation coefficients between predictors and dependent variables. There was a significant correlation between PD-partners MS score and PD-patients MS score ($\rho = .524$, $p \leq .001$). PD-patients' MS score had a significantly inverse correlation with PDQ8S ($\rho = -.516$, $p \leq .001$) and UPDRS III ($\rho = -.311$, $p = .026$) but not with caregiver burden and NMSQuest. PD-partners' MS score showed a significant inverse correlation with caregiver burden ($\rho = -.631$, $p \leq .001$), PDQ8SI ($\rho = -.409$, $p = .003$), and IQCODE

TABLE 1: Demographics and clinical features. $n = 51$ dyads.

		PD-patient	PD-partner
Female	n (%)	22 (43.1)	29 (56.9)
Level of education			
Elementary	n (%)	8 (15.7)	6 (11.8)
Secondary	n (%)	11 (21.6)	16 (31.4)
University	n (%)	32 (62.7)	29 (56.9)
Level of income (SEK)			
0–199,000	n (%)	13 (25.5)	13 (25.5)
200,000–450,000	n (%)	27 (52.9)	30 (58.8)
>450,000	n (%)	11 (21.6)	8 (15.7)
Retired*	n (%)	45 (88.2)	39 (76.5)
Working	n (%)	10 (19.6)	16 (31.4)
Total MS	m (SD)	3.2 (0.65)	2.9 (0.77)
Dimension of MS			
Love	md (IQR)	3.6 (0.67)	3.6 (1.0)
Shared pleasurable activities	md (IQR)	3.2 (1.25)	3.0 (1.25)
Shared values	md (IQR)	3.0 (1.0)	3.0 (1.5)
Reciprocity	md (IQR)	3.3 (1.0)	2.8 (1.67)
Total CBS	m (SD)		42.5 (15.8)
PD-duration	m (SD)	8.4 (6.4)	
PDQ8SI	m (SD)	27.4 (14.6)	
IQCODE	M (SD)	3.2 (.53)	
Hohen & Yahr	md (IQR)	2.0 (1)	
NMSQuest	m (SD)	12.1 (4.6)	
UPDRS III	m (SD)	18.1 (5.8)	
PD-patients self-rating of motor signs			
Tremor	n (%)	28 (54.9)	
Bradykinesia	n (%)	43 (84.3)	
Rigidity	n (%)	38 (74.5)	
Gait	n (%)	35 (68.6)	

Notes: PD: Parkinson's disease, MS: mutuality scale, CBS: caregiver burden scale, PDQ8SI: the Parkinson's Disease Questionnaire Summary Index, IQCODE: Informant Questionnaire on Cognitive Decline in the Elderly, NMSQuest: Non-motor Symptoms Questionnaire, and UPDRS III: the Unified Parkinson's Disease Rating Scale-Part III.

*Some of the study subjects were still working.

($\rho = -.529, p \leq .001$) but not with NMSQuest and UPDRS III. Hoehn and Yahr stages had a significant correlation with mutuality, PD-patients' HRQoL, and caregiver burden.

3.5. Multivariate Linear Regression Analysis. Suspect multicollinearity (tolerance = $\leq .5$, $\rho = \geq .5$) was detected between some of the included predictors. They were removed one by one and the variable that remained was the one with tolerance $> .5$, highest adjusted R^2 value, and the best fit regarding the assumptions of regression analysis. Contribution of each predictor to explain variance in the final multivariate regression models is presented in Table 5.

3.5.1. PD-Patients' Mutuality. In the final model with PD-patients' MS as the DV, the included predictors explained 31.6% of the variance. Of them, PD-partners' MS score ($\beta = .419, p = .002$) and gender of the PD-partners ($\beta = .332, p = .017$) contributed most of the explained variance.

Consequently, PD-patients' mutuality score was higher in those with a male partner and partners with high level of mutuality.

3.5.2. PD-Patients' HRQoL. With PDQ8SI as the DV, the included predictors explained 49.7% of the variance. PD-patients' MS score ($\beta = -.433, p = .001$) and NMSQuest score ($\beta = .498, p \leq .001$) contributed significantly to the explained variance of PDQ8SI scores. In other words, patients with high level of mutuality had significantly better HRQoL (lower PDQ8SI), while an increasing frequency of NMS decreases the HRQoL.

3.5.3. PD-Partners' Mutuality. The included predictors explained 28.9% of the variability in PD-partners' MS scores. PD-patients' MS score ($\beta = .461, p = .002$) and increased impairment of cognition ($\beta = -.314, p = 0.016$) contributed significantly to PD-partners' mutuality.

TABLE 2: PD-patients* self-rated frequency of non-motor symptoms. $n = 51$.

	Yes <i>n</i> (%)
Dribbling	22 (43.1)
<i>Taste/smelling</i>	28 (54.9)
Swallowing	19 (37.3)
Vomiting	7 (13.7)
Constipation	25 (49.0)
Bowel incontinence	8 (15.7)
<i>Bowel emptying incomplete</i>	26 (51.0)
<i>Urgency</i>	38 (74.5)
<i>Nocturia</i>	40 (78.4)
Pain	17 (33.3)
Weight	12 (23.5)
Remembering	25 (49.0)
Loss of interest	12 (23.5)
Hallucinations	15 (29.4)
<i>Concentrating</i>	28 (54.9)
Sad, blues	24 (47.1)
Anxiety	20 (39.2)
Sex drive	16 (31.4)
<i>Sex difficulty</i>	27 (52.9)
<i>Dizzy</i>	33 (64.7)
Falling	25 (49.0)
Day time sleepiness	11 (21.6)
<i>Insomnia</i>	28 (54.9)
Intense vivid dreams	16 (31.4)
Acting out during dreams	18 (35.3)
<i>Restless legs</i>	27 (52.9)
Swelling	12 (23.5)
Sweating	14 (27.5)
Diplopia	20 (39.2)
Delusions	6 (11.8)

* PD: Parkinson's disease.

Italics: frequency > 50%.

3.5.4. *Caregiver Burden.* The explained variance of the included predictors in the model with CBS as the DV was calculated as 52.7%. PD-partners with high MS score ($\beta = -.559, p \leq .001$) experienced less caregiver burden. A worsening of PD-patients' cognition increased the CBS score although it did not reach statistical significance ($\beta = .219, p = .050$).

4. Discussion

4.1. *Major Findings.* Consistent with the result of other dyadic research with stroke patients and frail elderly, the average MS score was quite high and the patients tend to rate their mutuality higher than their caregivers [17, 18, 34]. However, in the present study the difference was not significant except for the dimension of reciprocity. This is

the first study, to the best of our knowledge, to explore mutuality from the PD-patient's perspective. We found that PD-patients with high level of mutuality also experienced high HRQoL. Similar result has been shown in a study of patients with dementia [35]. Furthermore, having a male partner was associated with higher rated level of mutuality, but not with better HRQoL. Research so far is inconsistent regarding gender and HRQoL even if Martinez-Martin et al. (2008) observed more anxiety and worse HRQoL in female caregivers [4, 36]. Mutuality has also been reported as a protective factor of caregiver burden, which is in line with our result showing that PD-partners who perceived high mutuality also experience lower caregiver burden [9, 11, 37, 38].

Both motor and NMS were correlated with the MS, PDQ8SI, and CBS scores even though neither H/Y nor UPDRS III significantly contributed to the explained variances in the subsequent regression analysis. According to prior research, it seems that NMS such as depression, impaired cognition, sleep disorders, and fatigue have a larger impact on PD-patients' HRQoL than motor symptoms [3, 5, 39–41]. Similar result has also been reported regarding caregivers' mutuality showing gait impairment correlating with mutuality but not as a significant predictor [14]. The negative impact of NMS on PD-patients' HRQoL and impaired cognition on caregiver burden was expected and has also been reported in an extensive literature review by Chaudhuri [1].

Another interesting finding which has not been reported, as far as we know, was that mutuality scored by one member of the dyad was the strongest contributor of the level of mutuality experienced by the other member of the dyad. Using the modified stress-appraisal model but with a dyadic perspective [9, 20], some of our results could hypothetically be explained by the relatively high reported frequencies of NMS such as sleeping difficulties (55%), nocturia (78%), and restless legs (53%). These NMS, if protracted and severe enough, may not only disturb the PD-patients but also negatively affect their partners in various aspects such as sleep quality. Furthermore, impaired concentration (55%) and dizziness (65%), which were commonly reported in this study, may also affect the partners' wellbeing through worries of fall and need of adaptation or adjustment of daily activities. On the other hand, it may also affect the patients' wellbeing due to an increased experience of dependency and loss of the role as a partner. Altogether, the balance of responsibilities, interdependency, and roles may alter and put a strain on the relationship. This is reflected in our results by the significant difference in the MS dimension of reciprocity. However, if the dyads succeed to find gratification, meaning, and support, high mutuality may ameliorate negative outcomes such as burden and improve HRQoL even though the disease severity worsens by time. Overall, our results encourage a dyadic perspective due to the potential impact perceived mutuality has on HRQoL and caregiving burden when evaluating PD-symptoms and tailoring interventions. Paying attention to the experience of mutuality by both members of the dyad will allow clinicians to detect high risk dyads and look for interventions that address the patient's and their partner's

TABLE 3: Frequency of PD-patients* who need help in different daily activities. $n = 51$.

	No help		Supervision		Some help		All help	
	<i>n</i>	(%)	<i>n</i>	(%)	<i>n</i>	(%)	<i>n</i>	(%)
Grooming/dressing	40	78.4	6	11.8	4	7.8	1	2.0
Bath/shower	38	74.5	6	11.8	5	9.8	2	3.9
Food intake	44	86.3	2	3.9	5	9.8	0	
Toileting	42	82.4	3	5.9	5	9.8	1	2.0
Walking/transferring	28	54.9	6	11.8	15	29.4	2	3.9
Cooking/cleaning	23	45.1	2	3.9	16	31.4	10	19.6
Shopping	19	37.3	1	2.0	21	41.2	10	19.6

*PD: Parkinson's disease.

TABLE 4: Spearman rank correlation coefficients between independent variables and dependent variables. $n = 51$ dyads.

	PD-patient MS		PDQ8SI		PD-partner MS		CBS	
	Rho	<i>p</i> value	Rho	<i>p</i> value	Rho	<i>p</i> value	Rho	<i>p</i> value
PD-patient MS	1.00							
PDQ8SI	-.516	<.001	1.00					
PD-partner MS	.524	<.001	-.409	.003	1.00			
CBS	-.262	.063	.292	.038	-.631	<.001	1.00	
UPDRS III	-.311	.026	.322	.021	-.255	.071	.286	.042
H/Y	-.290	.039	.413	.003	-.309	.027	.336	.016
NMSQuest	-.178	.212	.631	<.001	-.252	.074	.258	.067
IQCODE	-.229	.107	.285	.042	-.529	<.001	.618	<.001
Cohabitation	.056	.695	-.013	.925	.072	.614	-.296	.035
PD-duration	-.199	.171	.085	.563	-.100	.495	.053	.715

Notes: PD: Parkinson's disease, PDQ8SI: the Parkinson's Disease Questionnaire Summary Index, MS: mutuality scale, CBS: caregiver burden scale, NMSQuest: the Non-motor Symptom Questionnaire, UPDRS III: the Unified Parkinson's Disease Rating Scale-Part III, H/Y: Hohen & Yahr, and IQCODE: Informant Questionnaire on Cognitive Decline in the Elderly.

wellbeing. Interventions such as social support, respite care, couple therapy, or counseling may help the couple to adapt and adjust to the ever changing care situation and find inner strength to cope. This will allow the medical system to provide a quality collaborative care that can improve patient outcomes and ameliorate caregiver burden.

4.2. Limitations. The present study has some limitations. First, we have only explored disease-related factors and mutuality association with the dependent variables of interest in our study. This is shown by the relatively low explained variance in the regression models. Future research would benefit from exploring models with measurement of both PD-related and general factors affecting the caregiving situation. However, our results provide a starting point for future studies with a dyadic perspective in PD. Secondly, the cross-sectional design and the rather small sample size with predominance of patients with mild to moderate PD limit the generalizability and possibility of causal inferences. Nevertheless, this was the initial analysis of baseline data within an ongoing longitudinal study, and we are anticipating data that will enable assessment of changes during the follow-up. Thirdly, the use of PDQ8 as measurement of HRQoL may not assess all suggested domains of the concept HRQoL. However, PDQ8 is a validated and a commonly used

questionnaire in PD research and enabled us to compare our research with others.

5. Conclusion

The main findings of our study suggest that high level of mutuality experienced by the PD-patient was associated with their HRQoL. This was also shown in the PD-partner sample with an association between mutuality and burden. Furthermore, level of mutuality scored by one member of the dyad was shown to be a dominant contributor to the other member's mutuality. We do acknowledge that more research is needed including both PD-related and general factors in different PD settings. In general, it seems that NMS contribute to a larger extent to the mutual relationship in PD-affected dyads than motor disabilities.

Competing Interests

Dag Aarsland has received honoraria or research support from Lundbeck, Inc., Novartis, GE Healthcare, and Glaxo-SmithKline and serves on the editorial boards of International Psychogeriatrics, Movement Disorders, and the Journal of Neurology, Neurosurgery, and Psychiatry. The other authors have no conflict of interests to report.

TABLE 5: Multiple linear regression analysis to find predictors of the Parkinson's Disease Summary Index (PDQ8SI), caregiver burden scale, PD-patient mutuality, and PD-partner mutuality. $n = 51$ dyads.

	Unstandardized coefficients	Standardized coefficients	<i>p</i> value	95% CI	Tolerance/VIF
<i>Dependent variable = PD-patient MS Adj R² = .316</i>					
Predictors					
<i>PD-partner MS</i>	.356	.419	.002	.143–.569	.882/1.134
UPDRS III	–.023	–.205	.113	–.052–.006	.852/1.174
NMS	–.025	–.176	.169	–.061–.011	.866/1.155
<i>PD-partner gender*</i>	.434	.332	.017	.080–.788	.759/1.318
Education**	.144	.110	.366	–.173–.461	.938/1.066
PD-partner age	–.001	–.016	.902	–.020–.018	.768/1.302
<i>Dependent variable = PDQ8SI Adj R² = .497</i>					
Predictors					
<i>PD-patient MS</i>	–9.655	–.433	.001	–14.862––4.449	.752/1.330
UPDRS III	.090	.036	.749	–.475–.655	.814/1.228
NMS	1.592	.498	<.001	.871–2.313	.803/1.245
IQCODE	.034	.032	.762	–.190–.257	.911/1.097
PD-partner gender*	–4.329	–.148	.234	–11.565–2.907	.666/1.500
Education**	–3.353	–.115	.275	–9.471–2.766	.924/1.083
PD-partner age	–.190	–.121	.293	–.551–.171	.778/1.285
<i>Dependent variable = PD-partner MS Adj R² = .289</i>					
Predictors					
<i>PD-patient MS</i>	.542	.461	.002	.216–.869	.752/1.330
UPDRS III	–.013	–.101	.450	–.049–.022	.814/1.228
NMS	.011	.066	.621	–.034–.056	.803/1.245
IQCODE	–.017	–.314	.016	–.031–.003	.911/1.097
PD-partner gender*	.039	.025	.865	–.415–.492	.666/1.500
Education**	–.117	–.076	.543	–.500–.267	.924/1.083
PD-partner age	–.009	–.104	.446	–.031–.014	.778/1.285
<i>Dependent variable = CBS Adj R² = .527</i>					
Predictors					
<i>PD-partner MS</i>	–11.541	–.559	<.001	–16.149––6.933	.771/1.296
UPDRS III	.447	.163	.129	–.136–1.030	.852/1.174
NMS	.282	.081	.449	–.462–1.026	.839/1.191
IQCODE	.251	.219	.050	.000–.503	.802/1.247
PD-partner gender*	3.023	.095	.400	–4.143–10.188	.756/1.322
Education**	1.178	.037	.713	–5.250–7.607	.931/1.074
PD-partner age	–.253	–.148	.191	–.636–.131	.768/1.302

Notes: PD: Parkinson's disease, PDQ8SI: the Parkinson's Disease Questionnaire Summary Index, MS: mutuality scale, CBS: caregiver burden scale, NMSQuest: the Non-motor Symptom Questionnaire, UPDRS III: the Unified Parkinson's Disease Rating Scale-Part III, and IQCODE: Informant Questionnaire on Cognitive Decline in the Elderly. Italics: significant predictors.

*PD-partner gender = 0 = female, 1 = male.

**Education = 0 = either elementary, secondary, or only one with university education and 1 = both with university education.

Acknowledgments

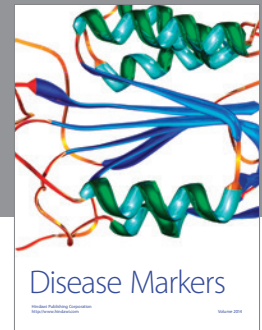
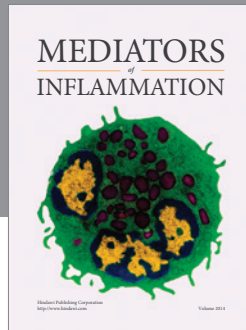
The authors would like to thank all the participants. The study was supported by The Parkinson Foundation in Sweden with Grant no. 663/14.

References

- [1] K. R. Chaudhuri, *Handbook of Non-Motor Symptoms in Parkinson's Disease*, Springer, Dordrecht, The Netherlands, 2012.
- [2] J. Lökk, "Caregiver strain in Parkinson's disease and the impact of disease duration," *European Journal of Physical and Rehabilitation Medicine*, vol. 44, no. 1, pp. 39–45, 2008.
- [3] D. Aarsland, J. P. Larsen, K. Karlsen, N. G. Lim, and E. Tandberg, "Mental symptoms in Parkinson's disease are important contributors to caregiver distress," *International Journal of Geriatric Psychiatry*, vol. 14, no. 10, pp. 866–874, 1999.
- [4] P. Martinez-Martin, C. Rodriguez-Blazquez, and M. J. Forjaz, "Quality of life and burden in caregivers for patients with Parkinson's disease: concepts, assessment and related factors,"

- Expert Review of Pharmacoeconomics & Outcomes Research*, vol. 12, no. 2, pp. 221–230, 2012.
- [5] B. Müller, J. Assmus, K. Herlofson, J. P. Larsen, and O.-B. Tysnes, “Importance of motor vs. non-motor symptoms for health-related quality of life in early Parkinson's disease,” *Parkinsonism and Related Disorders*, vol. 19, no. 11, pp. 1027–1032, 2013.
- [6] P. Martinez-Martin, “An introduction to the concept of ‘quality of life in Parkinson's disease,’” *Journal of Neurology*, vol. 245, supplement 1, pp. S2–S6, 1998.
- [7] S. Carretero, J. Garcés, F. Ródenas, and V. Sanjosé, “The informal caregiver's burden of dependent people: theory and empirical review,” *Archives of Gerontology and Geriatrics*, vol. 49, no. 1, pp. 74–79, 2009.
- [8] L. K. George and L. P. Gwyther, “Caregiver well-being: a multidimensional examination of family caregivers of demented adults,” *The Gerontologist*, vol. 26, no. 3, pp. 253–259, 1986.
- [9] B. Goldsworthy and S. Knowles, “Caregiving for Parkinson's disease patients: an exploration of a stress-appraisal model for quality of life and burden,” *Journals of Gerontology—Series B Psychological Sciences and Social Sciences*, vol. 63, no. 6, pp. P372–P376, 2008.
- [10] E. O. Park and K. L. Schumacher, “The state of the science of family caregiver-care receiver mutuality: a systematic review,” *Nursing Inquiry*, vol. 21, no. 2, pp. 140–152, 2014.
- [11] P. G. Archbold, B. J. Stewart, M. R. Greenlick, and T. Harvath, “Mutuality and preparedness as predictors of caregiver role strain,” *Research in Nursing & Health*, vol. 13, no. 6, pp. 375–384, 1990.
- [12] P. Archbold, B. J. Stewart, M. R. Greenlick, and T. A. Harvath, “The clinical assessment of mutuality and preparedness in family caregivers to frail older people,” in *Key Aspects of Elder Care: Managing Falls, Incontinence, and Cognitive Impairment*, Funk SG, E. M. Tornquist, M. T. Champagne, and R. A. Wise, Eds., pp. 328–339, Springer, New York, NY, USA, 1992.
- [13] J. H. Carter, B. J. Stewart, P. G. Archbold et al., “Living with a person who has Parkinson's disease: the spouse's perspective by stage of disease,” *Movement Disorders*, vol. 13, no. 1, pp. 20–28, 1998.
- [14] H. Tanji, K. E. Anderson, A. L. Gruber-Baldini et al., “Mutuality of the marital relationship in Parkinson's disease,” *Movement Disorders*, vol. 23, no. 13, pp. 1843–1849, 2008.
- [15] S. Mavandadi, R. Dobkin, E. Mamikonyan, S. Sayers, T. Ten Have, and D. Weintraub, “Benefit finding and relationship quality in Parkinson's disease: a pilot dyadic analysis of husbands and wives,” *Journal of Family Psychology*, vol. 28, no. 5, pp. 728–734, 2014.
- [16] C. D. Morrow, K. Smentkowski, S. Schwartz et al., “Does spouse participation influence quality of life reporting in patients with Parkinson's disease?” *Quality of Life Research*, vol. 24, no. 1, pp. 245–249, 2015.
- [17] K. S. Lyons, A. G. Sayer, P. G. Archbold, M. C. Hornbrook, and B. J. Stewart, “The enduring and contextual effects of physical health and depression on care-dyad mutuality,” *Research in Nursing and Health*, vol. 30, no. 1, pp. 84–98, 2007.
- [18] G. Pucciarelli, H. G. Buck, C. Barbaranelli et al., “Psychometric characteristics of the mutuality scale in stroke patients and caregivers,” *The Gerontologist*, vol. 56, no. 5, pp. e89–e98, 2016.
- [19] L. Ricciardi, M. Pomponi, B. Demartini et al., “Emotional awareness, relationship quality, and satisfaction in patients with parkinson's disease and their spousal caregivers,” *Journal of Nervous and Mental Disease*, vol. 203, no. 8, pp. 646–649, 2015.
- [20] K. Greenwell, W. K. Gray, A. van Wersch, P. van Schaik, and R. Walker, “Predictors of the psychosocial impact of being a carer of people living with Parkinson's disease: a systematic review,” *Parkinsonism and Related Disorders*, vol. 21, no. 1, pp. 1–11, 2015.
- [21] C. Jenkinson, R. Fitzpatrick, V. Peto, R. Greenhall, and N. Hyman, “The PDQ-8: development and validation of a short-form parkinson's disease questionnaire,” *Psychology and Health*, vol. 12, no. 6, pp. 805–814, 1997.
- [22] S. Elmståhl, B. Malmberg, and L. Annerstedt, “Caregiver's burden of patients 3 years after stroke assessed by a novel caregiver burden scale,” *Archives of Physical Medicine and Rehabilitation*, vol. 77, no. 2, pp. 177–182, 1996.
- [23] M. Caap-Ahlgren and O. Dehlin, “Factors of importance to the caregiver burden experienced by family caregivers of Parkinson's disease patients,” *Aging Clinical and Experimental Research*, vol. 14, no. 5, pp. 371–377, 2002.
- [24] U. S. Manskow, S. Sigurdardottir, C. Røe et al., “Factors affecting caregiver burden 1 year after severe traumatic brain injury: A Prospective Nationwide Multicenter Study,” *Journal of Head Trauma Rehabilitation*, vol. 30, no. 6, pp. 411–423, 2015.
- [25] M. Karlstedt, S. M. Fereshtehnejad, E. Winnberg, D. Aarsland, and J. Lökk, “Psychometric properties of the mutuality scale in Swedish dyads with Parkinson's disease,” *Acta Neurologica Scandinavica*, 2016.
- [26] M. M. Hoehn and M. D. Yahr, “Parkinsonism: onset, progression, and mortality,” *Neurology*, vol. 17, no. 5, pp. 427–442, 1967.
- [27] “Recent developments in Parkinson's disease. Edited by S. Fahn, C. D. Marsden, P. Jenner, and P. Teychenne New York, Raven Press, 1986 375 pp, illustrated,” *Edited*, vol. 22, no. 5, p. 672, 1987.
- [28] K. R. Chaudhuri, P. Martinez-Martin, A. H. V. Schapira et al., “International multicenter pilot study of the first comprehensive self-completed nonmotor symptoms questionnaire for Parkinson's disease: The NMSQuest Study,” *Movement Disorders*, vol. 21, no. 7, pp. 916–923, 2006.
- [29] A. F. Jorm, “The informant questionnaire on cognitive decline in the elderly (IQCODE): a review,” *International Psychogeriatrics*, vol. 16, no. 3, pp. 275–293, 2004.
- [30] K. H. Asberg and U. Sonn, “The cumulative structure of personal and instrumental ADL. A study of elderly people in a health service district,” *Scandinavian Journal of Rehabilitation Medicine*, vol. 21, no. 4, pp. 171–177, 1988.
- [31] Z. S. Nasreddine, N. A. Phillips, V. Bédirian et al., “The montreal cognitive assessment, MoCA: a brief screening tool for mild cognitive impairment,” *Journal of the American Geriatrics Society*, vol. 53, no. 4, pp. 695–699, 2005.
- [32] J. Cohen, *Statistical Power Analysis for the Behavioral Sciences*, L. Erlbaum Associates, Hillsdale, NJ, USA, 1988.
- [33] B. G. Tabachnick, *Using Multivariate Statistics*, Pearson Education, Boston, Mass, USA, 2012.
- [34] S. K. Ostwald, M. P. Bernal, S. G. Cron, and K. M. Godwin, “Stress experienced by stroke survivors and spousal caregivers during the first year after discharge from inpatient rehabilitation,” *Topics in Stroke Rehabilitation*, vol. 16, no. 2, pp. 93–104, 2009.
- [35] H.-L. Huang, L.-C. Weng, Y.-H. Tsai et al., “Predictors of self- and caregiver-rated quality of life for people with dementia living in the community and in nursing homes in northern Taiwan,” *International Psychogeriatrics*, vol. 27, no. 5, pp. 825–836, 2015.

- [36] P. Martinez-Martin, S. Arroyo, J. M. Rojo-Abuin et al., "Burden, perceived health status, and mood among caregivers of Parkinson's disease patients," *Movement Disorders*, vol. 23, no. 12, pp. 1673–1680, 2008.
- [37] Y.-I. L. Shyu, C.-T. Yang, C.-C. Huang, H.-C. Kuo, S.-T. Chen, and W.-C. Hsu, "Influences of mutuality, preparedness, and balance on caregivers of patients with dementia," *The journal of nursing research : JNR*, vol. 18, no. 3, pp. 155–163, 2010.
- [38] C.-Y. Hsiao and Y.-F. Tsai, "Caregiver burden and satisfaction in families of individuals with schizophrenia," *Nursing Research*, vol. 63, no. 4, pp. 260–269, 2014.
- [39] Z. Qin, L. Zhang, F. Sun et al., "Health related quality of life in early Parkinson's disease: impact of motor and non-motor symptoms, results from Chinese levodopa exposed cohort," *Parkinsonism and Related Disorders*, vol. 15, no. 10, pp. 767–771, 2009.
- [40] G. W. Duncan, T. K. Khoo, A. J. Yarnall et al., "Health-related quality of life in early Parkinson's disease: the impact of nonmotor symptoms," *Movement Disorders*, vol. 29, no. 2, pp. 195–202, 2014.
- [41] S.-M. Fereshtehnejad, M. Shafieesabet, F. Farhadi et al., "Heterogeneous determinants of quality of life in different phenotypes of Parkinson's disease," *PLoS ONE*, vol. 10, no. 9, Article ID e0137081, 2015.



Hindawi
Submit your manuscripts at
<https://www.hindawi.com>

