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Discordance Between Reports of Internalized Symptoms in Persons with Parkinson's Disease and Informants: Results from an Online Survey

Rini I. Kaplan, M.A., M.Sc.[1]*, Celina Pluim McDowell, M.A.[1]*, Juliana Wall, B.S.[1], Shraddha B. Kinger, M.A.[1], Robert D. Salazar, Ph.D.[1], Sandy Neargarder, Ph.D.[1,2], & Alice Cronin-Golomb, Ph.D.[1]

[1]Department of Psychological and Brain Sciences, Boston University, Boston, MA 02215, USA;

[2]Department of Psychology, Bridgewater State University, Bridgewater, MA 02325, USA

*Shared first authorship

Corresponding author: Alice Cronin-Golomb, Department of Psychological and Brain Sciences, Boston University, 900 Commonwealth Avenue, Boston, MA, 02215. Telephone: (617) 353-3911; E-mail: alicecg@bu.edu

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Abstract

Background: Self-report of motor and non-motor symptoms is integral to understanding daily challenges of persons with Parkinson's disease (PwPD). Care partners are often asked to serve as informants regarding symptom severity, raising the question of concordance with PwPD self-reports, especially regarding internalized (not outwardly visible) symptoms.

Objectives: Concordance between PwPD and informant ratings of motor and non-motor symptoms was evaluated across multiple domains.

Methods: In 60 PwPD-informant pairs, we compared ratings on 11 online self-report measures comprising 33 total scores, 2/3 of which represented purely internalized symptoms. For discordant scores, multiple regression analyses were used to examine demographic/clinical predictors.

Results: Though concordant on 85% of measures, PwPD endorsed more non-motor symptoms, bodily discomfort, stigma, and motor symptoms than informants. For PwPD, younger age, greater disease severity, and female gender predicted discordance.

Conclusions: Discordance between PwPD and informants on measures assessing symptoms that cannot be outwardly observed may require targeted education.

The motor and non-motor symptoms of Parkinson's disease (PD) affect quality of life (QoL) for persons with PD (PwPD) and their care partners (1,2). Care partners often serve as informants to family, friends, and healthcare professionals when self-reported symptoms from PwPD may not be attainable or reliable due to cognitive impairment, communication difficulties, or lacking insight into their condition (3–5). Consequently, self- and informant-based reports of motor and non-motor symptoms are frequently used interchangeably in clinical and research settings. It is unclear, however, whether informant ratings provide equivalent information to self-ratings. Informants may have difficulty identifying subtle symptoms in PwPD, or their ratings may be influenced by their own experiences of depression or burden (5–7). Further, informants who do not live with PwPD may over- or under-estimate the frequency and severity of symptoms.

The concordance of symptom reports is understudied, with mixed findings to date. Two studies assessing the agreement between PwPD- and informant-rated disability and motor function, as well as trained raters (e.g., neurologists), showed overall agreement on motor symptoms measured by the Movement Disorder's Society Unified Parkinson's Disease Rating Scale Motor Activities of Daily Living (MDS-UPDRS_m; 8,9). Notably, Parveen (9) found that externally observable symptoms (e.g., gait and resting tremor) demonstrated higher concordance of judgment than did less observable symptoms (e.g., rigidity). A study of motor symptoms and activities of daily living (ADLs) found that although PwPD and informant ratings of motor symptoms and ADLs were strongly correlated, PwPD rated themselves as less impaired and more independent than informants did on ADLs, which was interpreted as lack of insight due to basal ganglia dysfunction (3). Studies assessing neuropsychiatric symptom concordance (e.g., apathy, depression, anxiety) demonstrated low agreement, with PwPD rating their symptoms as more severe overall than informants (7,10,11). Studies of QoL, an outcome influenced more by non-motor than motor PD symptoms (12), reported either agreement overall (13) or discordance on overall ratings (14) or in certain QoL domains (13,15). Concordance between PwPD and informant ratings of stigma perception, another non-motor symptom of PD associated with worse QoL (16,17), has yet to be examined.

Because clinicians and researchers may use PwPD and informant reports of PD symptoms and QoL interchangeably, there is a need to assess the acceptability of this practice. We examined concordance between ratings of motor and non-motor symptoms and QoL by PwPD and their informants, hypothesizing that there would be discordance with regard to internalized symptoms (e.g., anxiety, depression, stigma). To assess this, we included multiple measures of internalized symptoms as well as measures of externalized (outwardly observable) symptoms (e.g., tremor, mobility).

Method

Participants were enrolled in the Boston University Online Survey Study of Parkinson's Disease (BOSS-PD), a study evaluating the experience of living with PD; see (16). PwPD who expressed interest in the study were asked if they had an informant (a spouse, close family member, significant other, or a close associate) who interacted regularly with them and was willing to participate. Informants provided consent and were sent online questionnaires regarding their perception of how the PwPD was functioning. Of the 347 PwPD, 60 informants also enrolled. The PwPD-informant pairs are described in Table 1.

BOSS-PD Questionnaires

Eleven self-report questionnaires assessed non-motor symptoms (including depression, anxiety, apathy, and stigma), motor and non-motor experiences of daily living (Table 1). Many questionnaires had subscales, resulting in 33 total scores. Of these, 22 reflected internalized symptoms, 7 externalized symptoms, and 4 mixed symptoms (a combination of internalized and externalized symptoms); total scores consisted of both internalized and externalized subscales.

Statistical Analysis

We conducted paired samples t-tests (PwPD vs. informant) for each (sub)scale, with alpha set to .01 to account for multiple comparisons. For each, a difference score was calculated by subtracting the informant score from the PwPD score. Positive difference scores indicated that PwPD endorsed more symptoms than informants; negative difference scores indicated that PwPD endorsed fewer symptoms. The difference score was correlated (Pearson or point-biseral when applicable) with demographic and clinical variables: PwPD motor symptom rating ($MDS\text{-}UPDRS_m$) was used as a proxy for disease severity. Multiple regression analyses were conducted for significantly discordant measures, with difference scores as the criterion and significantly correlated demographic and disease variables entered as predictors. Intraclass correlation coefficients (ICC) were also calculated with a one-way random effects model to examine inter-rater reliability between PwPD and informants. ICC values were interpreted as follows regarding agreement: .80 and above, excellent; .60-.80, good; .40-.60, moderate; $\leq$.40, poor (18).

Results

PwPD and informant characteristics and statistical results are presented in Tables 1 and 2. Paired samples t-tests revealed concordance on 28/33 symptom measures (19/22 internalized, 5/7 externalized, and 4/4 mixed). ICC analyses revealed good agreement on 4/33 (4/7 externalized) and moderate agreement on 9/33 (6/22 internalized, 0/7 externalized, 2/4 mixed). There were no ICC differences when comparing PwPD men and women. Discrepancies between the t-test and ICC results may be due to the paired nature of t-tests versus the group-level analyses of ICC.

Internalized Symptoms

T-tests revealed significant discordance on the non-motor symptoms questionnaire (NMSQuest) total score, Parkinson's Disease Questionnaire (PDQ-39) bodily discomfort subscale, and PDQ-39 stigma subscale, with PwPD endorsing more symptoms than informants in each case (all p's<0.01). Additionally, there was a trend for PwPD to report more symptoms on the Parkinson's Anxiety Scale (PAS) avoidance subcale and MDS-UPDRS Non-Motor Activities of Daily Living (MDS-UPDRS$_{nm}$) subscale (p's<0.05, >.01). ICC analyses revealed moderate agreement for the PDQ-39 Cognition, NeuroQoL Fatigue, NeuroQoL Cognition, BDI-II, BAI, and SSCI Internalizing.

The PDQ-39 Stigma difference score correlated with younger age (r(58)=-0.29, *p*<0.05) and greater disease severity ($MDS\text{-}UPDRS_m$; r(58)=0.38, *p*<0.01). Younger age (β=-0.62) and greater disease severity (β=0.98) were significant predictors of PDQ-39 Stigma difference scores (R^2=0.26, F(2,57)=10.05, p<.001). The NMSQuest total difference score correlated with younger informant age (r(58)=-0.31, *p*<0.05) and PwPD gender (r(58)=0.27, p<0.05). PwPD female gender predicted greater NMSQuest total difference scores (β=2.13), with a trend for informant age (β=-0.1, p=0.06). The regression model was significant (R^2=0.13, F(2, 57)=4.29, p=0.02). There were no significant correlations with demographic/clinical variables for PDQ-39 Bodily Discomfort.

Externalized Symptoms

Discordance was found on the $MDS\text{-}UPDRS_m$, with PwPD endorsing more motor symptoms, and the Mental Health Consumers' Experience of Stigma Scale (Wahl) discrimination subscale, with informants endorsing more discrimination (p's<0.01). ICC analyses revealed good agreement for the PDQ-Mobility, PDQ-ADLs, NeuroQoL Social Relationships, and MDS-UPRDSm, and moderate agreement for the PDQ-Communication.

The $MDS\text{-}UPDRS_m$ difference score correlated with younger PwPD age (r(58)= -0.30, *p*<0.05), which predicted discordance in $MDS\text{-}UPDRS_m$, (β=-0.19) and was related to greater motor severity endorsed by PwPD than by informants (R^2=0.09, F(2,57)=5.79, p<.05). The difference score on Wahl-discrimination was not correlated with any demographic/clinical variables.

Discussion

PwPD and informants were concordant on 28 of 33 symptom measures, suggesting that proxy reports may be largely reliable. As hypothesized, there was discordance between PwPD and informants on several internalized measures, including PDQ-39 stigma and bodily discomfort, and NMSQ total scores.

Several mechanisms may underlie discordance for internalized symptoms, which cannot be directly observed and are inherently challenging to quantify. Even if care partners are aware that PwPD experience internalized symptoms, they may not realize their magnitude. PwPD may also have difficulty communicating their symptoms to care partners, due to depressed mood symptoms, apathy (19), or alexithymia, the inability to identify their own emotions (20,21). The interaction of clinical and demographic factors may further complicate care partners' ability to quantify PD symptoms. This study indicated that for PwPD, younger age, greater disease severity, and female gender, as well as informant age, were predictors of PwPD-informant discordance.

Regarding externalized symptoms, while this study generally supports prior research that PwPD- and informant-ratings are concordant, our finding of discordance on the MDS-UPDRS$_m$ does not align with the concordance observed by Martínez-Martín and colleagues (8), although we did find good agreement in our ICC analyses. Relative to that sample, ours was diagnosed with PD more recently and rated their motor symptoms as less severe. We found that younger age predicted MDS-UPDRS$_m$ discordance, suggesting that younger age or earlier disease stages may present challenges to accurate informant report.

This is the first study to examine PwPD-informant concordance on ratings of stigma perception, finding discordance on two different measures. This is particularly noteworthy given that care partners in this study endorsed remarkable consistency regarding anxiety, depression, apathy, and quality of life. Discrimination (Wahl subscale) was reported more by informants than PwPD, suggesting that these care partners were vigilant to external experiences. By contrast, informants endorsed less perceived (internalized) stigma than did the PwPD (PDQ-39 stigma). A growing body of PD stigma research highlights its impact on quality of life (17) and its prevalence, especially younger PwPD and in those with depression (16,21,22). Dissonance between one’s identity (e.g., female gender, younger age) and traditional cultural depictions of PD (elderly men with severe functional/physical impairments) may increase distress associated with unwanted stereotypes and social perceptions. Evidence-based therapies such as acceptance and commitment therapy, cognitive-behavioral therapy, or mindfulness, may assist in managing stigma perception (22). Stigma may also be reduced through education of PwPD and the general populace.

There were limitations to this study. Most participants were highly educated, non-Hispanic White, with generally mild-to-moderate PD severity, constraining our ability to generalize to other PwPD. The study was online, meaning that PD diagnosis and severity were based on self-report. We could not examine the possibility that PwPD with depression may have over-reported other symptoms. Of the 347 enrolled PwPD, only 60 identified informants who then enrolled, suggesting possible selection bias. Finally, the study included more measures of internalized than externalized symptoms, though this was motivated by our hypothesis.

In sum, our results indicate that while informant reports are largely reliable, steps should be taken to increase informants’ and clinicians’ awareness of internalized symptoms. Our findings also provide support for using self-report questionnaires to assess non-motor symptoms in healthcare settings, especially for internalized symptoms that may be difficult to express in typical clinical interactions. Future research may consider how support groups, and group or couples therapy, may aid in developing a shared understanding of internalized experiences. Identifying discrepant perceptions may be an important first step in validating the subjective burden of this diagnosis.

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Authors' Roles

1) Research project: A. Conception, B. Organization, C. Execution

2) Statistical analysis: A. Design, B. Execution, C. Review and Critique

3) Manuscript preparation: A. Writing of the first draft, B. Review and Critique

RIK: 1A, 1B, 1C, 2A, 2B, 3A

CPM: 1A, 1B, 2C, 3A, 3B

JW: 2B, 3B

SBK: 2C, 3B

RDS: 1A, 3B

SN: 2B, 2C, 3B

ACG: 1A, 1B, 2C, 3B

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Ethical Compliance

The study was approved by the Institutional Review Board of Boston University (protocol #1204E). We obtained consent from participants before they engaged in the study. We confirm that we have read the Journal's position on issues involved in ethical publication and affirm that this work is consistent with those guidelines.

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Table 1. Participant characteristics and comparison of PwPD and informants on questionnaires

	Category	PwPD Mean (SD)	Informant Mean (SD)	Paired Samples t-value	Difference Score Mean (SD)	ICC
Age (years)		65.6 (8.7)	62.3 (12.3)			
Education (years)		17.3 (2.2)	16.9 (2.7)			
Men:Women		35:25	20:40			
Disease Duration (years)		5.3 (4.1)				
Length of Relationship (years)		38.5 (12.1)				
Hours Spent per Week		126 (47.2)				
Relationship Type						
Spouse/Significant Other		53				
Child		4				
Other Family Member		2				
Friend		1				
Time Between PwPD and Informant Responses (Days)		15.8 (32.1)				
Parkinson's Disease Questionnaire (PDQ-39) (23)						
Total Score	M	22.5 (11.4)	19.9 (12.7)	1.7	2.6 (12.2)	.48
Stigma	I	13.4 (15)	0.4 (3.2)	6.5***	13 (15.5)	-.28
Cognition	I	26.9 (17.6)	25.6 (20.1)	0.5	1.3 (20)	.45
Bodily Discomfort	I	34.6 (19)	27.2 (19.3)	2.6**	7.4 (22)	.30
Emotional Wellbeing	I	20.8 (14.4)	22.8 (17.4)	0.8	-2.1 (19.5)	.26
Social Support	I	19 (20.4)	20.6 (17.5)	0.5	-1.6 (23.3)	.25
Mobility	E	19.1 (20.3)	20.3 (23.1)	0.6	-1.2 (15.5)	.75
Activities of Daily Living	E	24.8 (19.7)	21.5 (21.3)	1.4	3.3 (18)	.61
Communication	E	21.7 (18.4)	20.6 (22.1)	0.4	1.1 (21.2)	.46
Quality of Life in Neurological Disorders (Neuro-QoL) (24)						
Total Score	M	116.3 (8.3)	114.1 (16.7)	1.1	3.1 (18.9)	-.20
Anxiety⁺	I	12.7 (5.5)	12.5 (5.7)	0.4	0.4 (7.2)	.26
Fatigue⁺	I	17 (7)	16.2 (6.3)	0.1	-0.1 (6.2)	.49
Positive Affect & Wellbeing⁺	I	36.6 (7.4)	37.9 (5.7)	1.0	-1.1 (7.7)	.30
Cognition⁺	I	33 (6.2)	33.7 (6.7)	1.0	-0.9(6.5)	.52
Social Relationships⁺	E	35.1 (6.2)	35.2 (6.2)	1.4	1 (4.7)	.64
Non-Motor Symptom Questionnaire (NMSQuest) (25)						
Total # of Symptoms	I	10.9 (4.4)	9 (5.5)	2.8**	1.9 (5.3)	.25
Frequency of Symptoms	I	33.1 (16.6)	29 (20)	1.4	4.1 (22.4)	.38
Movement Disorders Society Unified Parkinson's Disease Rating Scale (MDS-UPDRS) (26)						
Non-Motor Experiences of Daily Living ($MDS\text{-}UPDRS_{nm}$)	I	7.3 (3.7)	5.9 (4.2)	2.4*	1.4 (4.3)	.36

Motor Experiences of Daily Living (MDS-UPDRS$_m$)	E	11 (6.7)	9.1 (6.9)	2.6**	1.8 (5.4)	.66
Beck Depression Inventory (BDI-II) (27)						
Total Score	I	8.1 (6.1)	7.6 (6.8)	0.7	0.6 (6.6)	.48
Beck Anxiety Inventory (BAI) (28)						
Total Score⁺	I	6.9 (5.4)	5.6 (5.3)	1	0.8 (5.5)	.48
Parkinson's Anxiety Scale (PAS) (29)						
Total Score	I	6.6 (6.4)	5.6 (7.2)	1	1 (7.7)	.35
Persistent	I	4.2 (3.7)	3.8 (4.3)	0.8	0.5 (4.8)	.30
Episodic	I	1 (2.1)	1 (2.2)	0.2	-0.1 (2.4)	.37
Avoidance	I	1.3 (2)	0.8 (1.4)	2.1*	0.5 (1.9)	.34
Apathy Scale (AS) (30)						
Total Score⁺	I	9.6 (5.7)	9.6 (6.7)	0.3	2.2 (18.5)	.02
Stigma Scale for Chronic Illness (SSCI) (31)						
Total Score	M	35.2 (10.6)	34.5 (11.6)	0.5	0.7 (10.3)	.57
Internalizing	I	21.5 (7.4)	21.2 (8.2)	0.3	0.2 (7.3)	.57
Externalizing⁺	E	13.6 (3.6)	13.3 (4.5)	0.2	0.1 (4.5)	.39
Stigmatization Scale (SS) (32)						
Total Score⁺	I	41.9 (9.4)	40.2 (8.8)	1.4	2.3 (11.1)	.24
Mental Health Consumers' Experience of Stigma Questionnaire (Wahl) (33)						
Total Score⁺	M	34.8 (5.3)	36.1 (6.5)	2.0	-2.2 (7.6)	.12
Stigma ⁺	I	19.8 (3.8)	19.7 (4.2)	0.6	0.4 (4.3)	.31
Discrimination⁺	E	14.7 (3.84)	16.4 (5.5)	2.9**	-2.6 (6)	.03

*PwPD=persons with Parkinson's disease; Difference score calculated by subtracting informant rating from PwPD rating. Positive difference scores indicate PwPD endorsed more than informant. Negative difference scores indicate PwPD endorsed less than informant. Categories: M=Mixed, I=Internalized, E=Externalized. ⁺not completed by all participants, as follows: Neuro-QoL Anxiety, Fatigue, Positive Affect and Wellbeing, Cognition (PwPD N=60, informant N=47, PwPD-informant pair N=47). Neuro-QoL Total, Social Relationships (PwPD N=60, informant N=48, PwPD-informant pair N=48). SSCI Externalizing (PwPD N=58 PwPD, informant N=57; PwPD-informant pair N=55). BAI Total (PwPD N=54, informant N=47, PwPD-informant pair N=44). AS Total (PwPD N=54, informant N=47, PwPD-informant pair N=44). SS Total (PwPD N=54, informant N=48, PwPD-informant pair N=45). Wahl Total, Stigma, Discrimination (PwPD N=54, informant N=48, PwPD-informant pair N=45). *=p<0.05 (trend); **=p<0.01; ***=p<0.001. Alpha set to .01.*

Table 2. Correlations between difference scores on discordant measures and demographic variables.

	PDQ-39 Stigma	PDQ-39 Bodily Discomfort	NMSQuest Total # of Symptoms	Wahl Discrimination	MDS-UPDRS$_m$
PwPD Gender	-0.12	0.10	0.27*	-0.22	0.07
Informant Gender	0.07	-0.07	-0.16	0.12	-0.18
PwPD Age	-0.29*	-0.17	-0.17	-0.21	-0.30*
Informant Age	-0.20	-0.11	-0.31*	-0.07	-0.13
Length of Relationship	-0.24	-0.14	-0.08	-0.24	-0.10
Hours Spent per Week	0.09	-0.05	-0.23	0.01	0.07
Disease Severity +	0.38**	0.16	0.06	0.12	___
Disease Duration	0.05	0.13	-0.07	-0.01	0.07

*PwPD= persons with Parkinson's Disease; PDQ-39=Parkinson's Disease Questionnaire; NMSQuest=Non-Motor Symptom Questionnaire; Wahl=Mental Health Consumers' Experience of Stigma Scale; MDS-UPDRS$_m$=Movement Disorders Society Unified Parkinson's Disease Rating Scale Motor Experiences of Daily Living; += PwPD rated MDS-UPDRS$_m$ score used as a proxy for disease severity; *=$p<0.05$; **=$p<0.01$.*