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Stigma as a key determinant of health-related quality of life in Parkinson's disease

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Abstract

Purpose—People with Parkinson's disease (PD) may experience stigma due to their visible features of movement and communication difficulties. This paper aimed to examine the role of experienced stigma in health-related quality of life (QOL), after controlling for personal and clinical characteristics.

Methods—This is a preliminary analysis of a subset of baseline data from the Social Self-Management of Parkinson's Disease Study (SocM-PD), an ongoing 3-year prospective cohort study. 73 people with PD ($M_{age} = 65.72$, 29 women) participated in this study. Hierarchical multiple regression analyses were used to determine the role of stigma in QOL, after controlling for gender, disease severity, depression, and motor difficulties of daily living.

Results—Significant correlations were found between QOL with gender ($r = .26$), disease severity ($r = .38$), depression ($r = .65$), motor difficulties of daily living ($r = .71$), and stigma ($r = .83$). After controlling for the significant covariates, stigma made a significant and unique contribution to the explanation of QOL by 13.7 % ($p < 0.001$). A final hierarchical multiple regression with stigma and the 4 covariates revealed an overall model that explained 77.8% of the total variance of QOL ($F[5, 63] = 48.79, p < 0.001$).

Conclusions—Experienced stigma appears to be a key determinant of QOL in people with PD. The results suggest the importance of further understanding stigma in PD to develop possible

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Compliance with Ethical Standards

Conflict of interest The authors declare no conflict of interest.

Ethical approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed consent Informed consent was obtained from all individual participants included in the study.

intervention strategies. Future work is also needed to verify the results with a larger and longitudinal dataset of the SocM-PD.

Keywords

Enacted stigma; Felt stigma; Health-related quality of life; Parkinson's disease

Introduction

As first documented by Dr. James Parkinson in 1817 and later depicted in the classic picture by Gowers in 1896 [1], a person's Parkinson's disease (PD) can be observed from the masked face, stooped posture, clenched and trembling arms, and shuffling gait. The image connotes deformity and disability, which are likely to lead to a situation in which the individual is disqualified from full social acceptance, defined by Goffman as *stigma* [2].

Experience of stigma in people with PD has been described vividly and analyzed in-depth in qualitative research [3-7]. Stigma emerges from the interaction between the individual with PD and the “outside world”. People with PD may experience *felt stigma*, such as shame, embarrassment, and disgrace, and *enacted stigma* when encountering responses of others, such as staring, questioning, and avoiding, to their visible features of movement and communication difficulties [8]. Aware that their symptoms transmit a message of social incompetence and deviance, the individual with PD may try to disguise the symptoms and later withdraw from a public into a private world when they can no longer hide their symptoms.

Quantitative research also has validated the source of stigma by surveying public attitudes toward PD [9] and by examining others' impressions of PD symptoms [10-12]. Moore and Knowles reported that nearly half of survey respondents considered the disease to be stigmatizing [9]. And those who believed there was stigma had more negative attitudes toward PD. In addition, Tickle-Degnen et al. showed that facial masking may bias health care practitioners' views of people with PD as more depressed, less sociable, and less cognitively competent than their actual attributes [10]. Moreover, Hemmesch et al. reported that higher facial masking or higher abnormal bodily movement (including tremor and related abnormal movement) of individuals with PD elicited more negative first impressions in older adult observers [11, 12]. Due to both personal beliefs and public negative attitudes embedded in our society, people with PD are likely to feel stigmatized and thus suffer from psychological distress.

Health-related quality of life (QOL) is a broad construct pertaining to subjective well-being, taking into account body function, activity and participation, and environment. Therefore, it is likely that psychological distress and social withdrawal resulting from stigma would lead to decreased QOL. To the best of our knowledge, however, research in PD has only reported that stigma, measured in a subscale of a PD-specific QOL measure, is a determinant of depression [13]. No research has examined the degree to which stigma plays a role in overall feelings of quality of health in PD. In contrast, research about other diseases (e.g., epilepsy [14], HIV [15], lung cancer [16]) has documented that stigma predicted a significant amount of variance of QOL.

Identifying determinants of QOL is important to guide the development of interventions. In a systematic review of determinants of QOL in PD, the factors that have been examined include demographic variables, disease characteristics, non-motor symptoms, and motor symptoms [17]. Among the reviewed studies that used various factors and analysis models, depression was found to be the most constant predictor of QOL in the final model. In a later study with path analysis, in which depression was not included, motor difficulties of daily living as measured by the Unified Parkinson's Disease Rating Scale (UPDRS) Part II was reported to contribute the most to QOL in the model [18]. Given the above findings, it is of interest to know whether stigma would be a determinant of QOL in PD after controlling for depression and motor difficulties of daily living.

A series of studies by Tickle-Degnen on daily living with PD has demonstrated social concerns as a primary focus for individuals with PD [19]. In addition to the disease causing impairments in body function, PD is likely to interact with the socio-cultural context to influence QOL, as illustrated in our aforementioned review of stigma in PD. Therefore, the purpose of this project was to examine (1) the relationships of experienced stigma with clinical characteristics and QOL, (2) the role of stigma in predicting QOL after controlling for personal and clinical characteristics, and (3) the degree to which felt and enacted stigma would contribute to QOL.

Methods

Design

This paper analyzed a subset of baseline data from the Emergence and Evolution of Social Self-Management of Parkinson's Disease Study (SocM-PD), an ongoing 3-year prospective cohort study based in the New England area, US [19]. The primary aim of the SocM-PD is to study changes in the social lives and health of people with the disease and their caregivers (if there is one). The variables of stigma and quality of life are measured in the SocM-PD as two of several aspects of feelings of social comfort and well-being that are expected to contribute to social self-management trajectories over time. The current paper studies stigma-quality of life associations that are relevant to characterizing the SocM-PD trajectories of people with PD in future longitudinal analyses.

Participants

Participants were recruited through the Boston University Medical Center Parkinson's Disease Movement Disorder Clinic, postings on PD and aging research and advocacy websites, and PD support groups in the urban, suburban and rural regions within driving distance of the Boston metropolitan area. Inclusion criteria were (a) diagnosis of idiopathic PD utilizing the United Kingdom Parkinson's Disease Society Brain Bank clinical diagnostic criteria, (b) modified Hoehn and Yahr stage (H&Y) 1 through 4, (c) score ≥ 26 on the Mini-Mental Status Exam, (d) home setting within travel distance to study locations, (e) ability to communicate clearly and in English with research staff, (f) interested in participating and willing to provide informed consent. The H&Y (range 1 – 5) was used to evaluate the severity of PD: 1 means mild and 5 means severe. Participants were on antiparkinsonian medications. Protocols were approved by the institutional review boards of Boston

University and Tufts University. All participants provided written informed consent before the testing and interview began.

Measures

Measures reported in this paper were part of a larger interview and testing protocol of SocM-PD [19]. Study data were collected and managed using REDCap electronic data capture tools hosted at Tufts University [20]. REDCap (Research Electronic Data Capture) is a secure, web-based application designed to support data capture for research studies.

Stigma—The 24-item Stigma Scale for Chronic Illness (SSCI) was developed to measure stigma experienced by people with chronic neurological disorders including PD [8]. It contains two subscales: felt stigma and enacted stigma. The felt stigma scale asks questions about the respondent's feelings, for example, embarrassment, worry, and self-blame. The enacted stigma subscale asks questions about the behavior of others toward the respondent, for example, avoiding contact, staring, and being unkind. Each item is rated as 1 = never, 2 = rarely, 3 = sometimes, 4 = often, and 5 = always. A higher score indicates a higher frequency of experiencing stigma. A systematic review suggests that the SSCI has good content validity and fair internal consistency [21].

Depression—The 15-item Geriatric Depression Scale (GDS) is a self-report measure to detect depressive symptoms in older adults [22] and has been used in people with PD [23]. The GDS is reported to have adequate discriminant validity for a diagnosis of depressive disorder at a cutoff of 5, with a higher score meaning more depressive. In addition, the GDS is reported to have good internal consistency and test-retest reliability.

Motor difficulties of daily living—The Movement Disorder Society-Unified Parkinson's Disease Rating Scale (MDS-UPDRS) Part II is the second subscale of the MDS-UPDRS, which addresses self-perceived motor difficulties of daily living [24]. A higher score indicates a more severe impact of motor symptoms on the ability to complete activities of daily living. Clinimetric testing suggests satisfactory internal consistency and concurrent validity.

QOL—The 39-Item Parkinson's Disease Questionnaire (PDQ-39) assesses life concerns of people with PD [25]. It is composed of a summary index and eight domain scores – mobility, activities of daily living, emotional well-being, stigma, social support, cognition, communications, and bodily discomfort. A higher score indicates a more frequent self-perceived difficulty in QOL. Psychometric testing suggests that the PDQ-39 has adequate reliability and validity [26].

Statistical analyses

Descriptive statistics were used to summarize demographic and clinical characteristics, as well as scores in study measures. Pearson's correlation coefficients were computed between the study variables. The significance level was set to 0.05 (two-tailed). A Pearson's r of .10, .30, and .50 was considered as small, moderate, and strong association, respectively [27]. In addition, hierarchical multiple regression was used to estimate the contribution of stigma in

the explanation of the variance of QOL, after controlling for significant covariates. Finally, to explore the relative importance of felt vs. enacted stigma in the explanation of the variance of QOL, these two stigma scores were entered stepwise as independent variables into the hierarchical multiple regression model in addition to the covariates. Variable selection criteria were probability-of-F-to-enter less than .05, and probability-of-F-to-remove greater than .10. All analyses were performed by IBM SPSS statistics 22 for Windows.

Results

Table 1 shows the demographic and clinical characteristics of the study participants ($N = 73$). A majority of our participants (63%) had household income above \$50,000 USD, which was at the average-to-high income level in the New England area. Due to missing data on the PDQ-39 and SSCI, four participants were excluded pair-wise during statistical analyses. For SSCI, one participant never had any felt stigma, while 14 participants never had any enacted stigma (20.3%). About half of the participants experienced more-than-rare (≥ 2) felt stigma and 15.9% of the participants experienced more-than-rare enacted stigma. In addition, the participants reported significantly higher felt stigma than enacted stigma ($t(68) = 9.99, p < 0.001$).

Table 2 shows the Pearson's correlation coefficients among the study variables. Participants who experienced more stigma were more advanced in their disease, more depressed, and had more motor difficulties of daily living. In addition, overall stigma was significantly correlated with all domain scores of the PDQ-39, indicating increased problematic QOL with increased stigma. The correlation of stigma remained significant ($r > 0.68$) with QOL even when the stigma domain score was removed from the calculation of the overall PDQ-39 summary index (Tables A and B in Online Resource 1).

Participants who reported more problematic QOL were women and had more severe PD, more depressive symptoms, more motor difficulties of daily living and more experienced stigma. Those factors that were significantly correlated with the PDQ-39 summary index were entered into the regression model as covariates (i.e., gender, disease severity, depression, motor difficulties of daily living). A simultaneous multiple regression with the four covariates and stigma revealed an overall model that explained 77.8% of the total variance of the summary index ($F[5, 63] = 48.79, p < 0.001$, Table 3). Overall stigma provided a unique and significant explanation of the variance of QOL over and above that of the covariates, by 13.7% ($p < 0.001$). The results were similar when the stigma domain score was removed from the calculation of the summary index (Table C in Online Resource 1). When the domain scores of the PDQ-39 were entered as the outcome variable, overall stigma provided significant explanation of the variance in the domains of activities of daily living, emotional well-being, stigma, social support, and communications, in addition to that of the covariates.

Table 4 shows the results of the stepwise regression for felt and enacted stigma. Felt stigma entered the equation as contributing more explanation than enacted stigma to the amount of variance of the PDQ-39 summary index and domains of activities of daily living, emotional

well-being, stigma, social support, and communication. Separate regression analyses were also conducted for felt and enacted stigma with the covariates, and the results still indicated a better explanation of QOL by felt stigma (Tables D and E in Online Resource 1). The Variance Inflation Factor (VIF) values were below three in all the regression models, suggesting collinearity is not a problem in the analyses.

Discussion

The important findings of this study are that stigma appears to be a key determinant of QOL in people with PD. Those who reported higher stigma tended to have more severe PD, more depressive symptoms, more motor difficulties of daily living, and more problematic QOL. After controlling for gender, disease severity, depression, and motor difficulties of daily living, we found that stigma, especially felt stigma, made a significant and unique contribution to the explanation of the variance in QOL, including motor, emotional, and social domains. Stigma is included in the PDQ-39 as a concern of people with PD [25]. Our study elaborates on the role of stigma by providing empirical evidence for the contribution of stigma to QOL of PD.

Stigma has been a popular issue in diseases such as epilepsy, HIV, and lung cancer. However, research on stigma in PD is just in the beginning stage; only one study reported stigma as a determinant of depression [13]. Our findings of stigma as a key determinant of QOL are consistent with research in epilepsy [14], HIV [15], and lung cancer [16]. In PD, although many studies have examined determinants of QOL, those studies examined only features related to personal and clinical characteristics [17], and failed to include predictive factors emerging from interaction with the socio-culture context. Feeling stigmatized manifests itself when the individual with PD has to interact with others or has to show up in public. The significant contribution of stigma to QOL suggests that one's subjective well-being is inseparable from the socio-cultural context.

By breaking down overall stigma into felt and enacted stigma, we further found that felt stigma, compared to enacted stigma, was experienced by more participants and to a stronger degree (Table 1). Moreover, felt stigma appears to be the main type of stigma contributing to QOL. Our results are in parallel with research findings in epilepsy that felt stigma was more prevalent than enacted stigma and that felt stigma may be in its own right a profound source of psychological distress and QOL problems [28, 29].

Given the critical role of felt stigma in QOL, it is important to track where felt stigma may come from. In Corrigan and Watson's model, public attitudes lead to enacted stigma, which in turn results in felt stigma [30]. We conducted a *post hoc* mediation analysis to test this model with our data. Our results seem to support the model by finding a significant indirect effect of enacted stigma on QOL through felt stigma (95% CI = 4.22 — 12.02, $p < 0.05$, Online Resource 2), after controlling for depression and motor difficulties of daily living. Although the scores of enacted stigma suggest that most of our participants seldom experienced that others discriminated against them, it seems that even a slight encounter of discrimination aggravated their negative feelings about themselves from having PD (i.e., felt stigma). Moreover, we tested a reverse model whether enacted stigma would mediate the

relationship between felt stigma and QOL. Only a significant direct effect of felt stigma on QOL was found (95% CI = 5.22 – 13.00, $p < 0.05$, Online Resource 2). Overall the results suggest that felt stigma, compared to enacted stigma, has a stronger and more direct relationship with QOL.

In addition, some participants had felt stigma without having any enacted stigma ($n=13$, 18.84%). This may suggest that the perception of PD as stigmatizing may be anchored in what people with PD accept to be the commonly held view of PD and its visible symptoms among the lay community. In a survey of public attitudes toward PD, more than 70% of the respondents, some of whom might actually have PD, reported somewhat or greatly worried about potential consequences of PD, such as physical disability, being dependent on others, being a burden, and not being able to socialize [9]. As public attitudes shape the context in which people with PD live in, those negative attitudes toward PD and its symptoms are likely to become incorporated in one's self-perceptions. The negative self-perception of oneself may be one source of felt stigma once people get diagnosed [2].

In this study, participants with PD who experienced higher stigma were likely to also have more depressive symptoms and poorer QOL across motor, emotional, and social domains. The findings should raise the awareness of stigma of PD in health care professions and general public. As stigma is inseparable from the socio-cultural environment, it is important to recognize the social meaning of PD and PD-related symptoms. Future work with longitudinal data is needed to validate the temporal sequence of felt and enacted stigma for possible causal inference. In addition, examining moderating and mediating factors in the relationship between stigma and QOL may help develop intervention strategies. For example, would social resources, such as group musical or exercise classes consisting of a mix of people with and without PD, decrease the experience of stigma by individuals with PD and the negative attitudes towards PD in the general public? Would these changes mediate better QOL?

This paper presents preliminary results from a subset of baseline data from the ongoing 3-year SocM-PD project [19]. Some limitations of this study should be noted. First, shared negatively-worded questions in the SSCI, MDS-UPDRS II, and PDQ-39 may have exaggerated the correlation coefficients among these measures [31]. Second, the results that felt stigma, rather than enacted stigma, explained a significant amount of variance of QOL may be partly attributable to the score distribution that felt stigma had a larger variance than enacted stigma. Third, sampling bias may exist because most of our participants had at least bachelor's degree and were in relatively high socioeconomic status. Therefore, the results may not be generalizable to people with PD who have lower educational level or socioeconomic status. Our findings provide beginning evidence about one aspect of social life with PD, and should be verified with a larger and longitudinal dataset of the SocM-PD in the future.

Conclusions

This study provides preliminary evidence showing stigma, especially felt stigma, as a key determinant of QOL in PD. The results suggest the importance for health care practitioners

and general public to be aware of stigma issues related to PD and its symptoms. The results of this study should be verified with a larger and longitudinal dataset of the SocM-PD with on-going data collection. Future work is needed to identify moderating and mediating factors in the relationship between stigma and QOL to develop intervention strategies.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgments

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Table 1

Participants' characteristics (N=73)

	Frequency (%)	Mean \pm SD	Range
Male: Female	44:29 (60.3% : 39.7%)		
Age (N=73)		65.72 \pm 10.10	28.56-89.26
Living status (N=73)	Live alone: 12 (16.4%) Live with others: 61 (83.6%)		
Marital status (N=73)	Single and never married: 6 (8.2%) Married: 56 (76.7%) Separated/divorced/widowed: 11 (15.0%)		
Education (N=73)	High school: 10 (13.8%) College: 29 (39.7%) Graduate school: 34 (46.5%)		
Hoehn and Yahr stage (N=73)	I: 2 (2.7%) II: 53 (72.6%) III: 10 (13.7%) IV: 8 (11%)		1-4
Duration (year, N=72)		8.34 \pm 7.41	0.50-34
MMSE score (N=73)		29.16 \pm 1.13	26-30
GDS (N=73)		2.44 \pm 2.68	0-13
MDS-UPDRS II (N=73)		11.81 \pm 7.40	0-38
PDQ-SI (N=69)		27.49 \pm 14.65	7.19-75.94
SSCI overall stigma (N=69)	Below Rarely: 50 (72.5%) Rarely to below Sometimes: 14 (20.3%) Sometimes to below Often: 5 (7.2%)	1.79 \pm 0.60	1-3.58
Felt stigma	Below Rarely: 35 (50.7%) Rarely to below Sometimes: 26 (37.7%) Sometimes to below Often: 6 (8.7%) Often to below Always: 2 (2.9%)	2.06 \pm 0.74	1-4.08
Enacted stigma	Below Rarely: 58 (84.1%) Rarely to below Sometimes: 9 (13.0%) Sometimes to below Often: 2 (2.9%)	1.46 \pm 0.52	1-3.36

MMSE Mini-Mental Status Exam, *GDS* Geriatric Depression Scale, *MDS-UPDRS* Movement Disorder Society-Unified Parkinson's Disease Rating Scale, *PDQ-SI* 39-Item Parkinson's Disease Questionnaire-Summary Index, *SSCI* Stigma Scale for Chronic Illness

Table 2Pearson's correlation coefficients (*r*) between study variables (N=69)

	Gender	H&Y	GDS	MDS-UPDRS II	SSCI Overall stigma	SSCI Felt stigma	SSCI Enact stigma
H&Y	.138	--	--	--	--	--	--
GDS	.203	.230	--	--	--	--	--
MDS-UPDRS II	.101	.582 *	.436 *	--	--	--	--
SSCI overall stigma	.210	.339 *	.571 *	.614 *	--	--	--
Felt stigma	.220	.273 *	.615 *	.546 *	.963 *	--	--
Enacted stigma	.157	.391 *	.401 *	.624 *	.892 *	.736 *	--
PDQ-SI	.258 *	.382 *	.647 *	.712 *	.833 *	.820 *	.714 *
Mobility	.228 *	.544 *	.538 *	.693 *	.583 *	.557 *	.527 *
ADL	.091	.389 *	.554 *	.735 *	.672 *	.661 *	.576 *
Emotional well-being	.353 *	.205	.699 *	.476 *	.667 *	.711 *	.480 *
Stigma	.190	.141	.507 *	.531 *	.822 *	.825 *	.677 *
Social support	.101	.023	.177	.218	.416 *	.402 *	.369 *
Cognitions	.146	.228	.476 *	.457 *	.499 *	.497 *	.417 *
Communication	.063	.323 *	.435 *	.653 *	.672 *	.641 *	.611 *
Bodily discomfort	.272 *	.285 *	.298 *	.293 *	.402 *	.367 *	.390 *

H&Y Hoehn and Yahr stage, *GDS* Geriatric Depression Scale, *MDS-UPDRS* Movement Disorder Society-Unified Parkinson's Disease Rating Scale, *SSCI* Stigma Scale for Chronic Illness, *PDQ-SI* 39-Item Parkinson's Disease Questionnaire-Summary Index, *ADL* Activities of daily living. Gender was coded as 0 for men and 1 for women. The higher the scores, the more problematic the conditions.

* $p < 0.05$

Table 3

Hierarchical multiple regression with overall stigma.

PDQ-39																				
Mobility			Activities of daily living			Emotional well-being			Stigma		Social support		Cognitions		Communication		Bodily discomfort		SI	

Hierarchical multiple regression with felt and enacted stigma being entered stepwise

PDQ-39																
Mobility		Activities of daily living		Emotional well-being		Stigma		Social support		Cognitions		Communication		Bodily discomfort		SI
β	R^2	β	R^2	β	R^2	β	R^2	β	R^2	β	R^2	β	R^2	β	R^2	R^2
Variable Statistics																
Gender	.126	-.040		.190 [*]		.028		.029		.064		-.057		.217		.090
H&Y	.233 [*]	-.003		-.058		-.190 [*]		-.127		-.028		-.033		.268		.004
GDS	.261 [*]	.140		.391 [*]		-.031		-.12		.323		-.016		.169		.150 [*]
MDS-UPDRS II	.453 [*]	.598 [*]	.507 [*]	.089	.570	.232 [*]	.412	.094	.074	.319	.303	.450 [*]	.451	.107	.189	.658
Felt stigma	^a	.308 [*]	.049	.396 [*]	.082	.763 [*]	.303	.453 [*]	.107	--	--	.426 [*]	.095	--	--	.137
Enacted stigma	^a	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--
Total Model Statistics																
Adjusted R^2	.573		.621	.624		.693		.116		.259		.510		.138		.779
F	23.780		23.271	23.608		31.666		2.784		6.943		15.139		3.727		48.823
p	.000		.000	.000		.000		.025		.000		.000		.009		.000

PDQ-39 Item Parkinson's Disease Questionnaire, SI Summary Index, H&Y Hoehn and Yahr stage, GDS Geriatric Depression Scale, MDS-UPDRS Movement Disorder Society-Unified Parkinson's Disease Rating Scale, SSCI Stigma Scale for Chronic Illness

^{*} $p < 0.05$.

^a The predictor variable was not entered due to not meeting the selection criterion.