ORIGINAL ARTICLE

Difficulties in activities of daily living are associated with stigma in patients with Parkinson's disease who are candidates for deep brain stimulation

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Objective: Parkinson's disease (PD) is often accompanied by stigma, which could contribute to a worse prognosis. The objective of this study is to identify the variables associated with stigma in PD patients who are candidates for deep brain stimulation (DBS).
Methods: We investigated sociodemographic and clinical variables associated with stigma in a sample of 54 PD patients indicated for DBS. The independent variables were motor symptoms assessed by the Movement Disorder Society-sponsored revision of the Unified Parkinson Disease Rating Scale (MDS-UPDRS III), depressive symptoms measured by the Hospital Anxiety and Depression Scale, age, disease duration and the presence of a general medical condition. The Mobility, Activities of daily living and Emotional well-being domains of the 39-item Parkinson's Disease Questionnaire (PDQ-39) were also investigated as independent variables, and the Stigma domain of the PDQ-39 scale was considered the outcome variable.
Results: After multiple linear regression analysis, activities of daily living remained associated with the Stigma domain (B = 0.42 [95%CI 0.003-0.83], p = 0.048). The full model accounted for 15% of the variance in the Stigma domain (p = 0.03).
Conclusions: Although causal assumptions are not appropriate for cross-sectional studies, the results suggest that ADL difficulties could contribute to greater stigma in PD patients with refractory motor symptoms who are candidates for DBS.

Keywords: Activities of daily living; depressive symptoms; Parkinson's disease; quality of life; stigma

Introduction

Parkinson's disease (PD) is the second most common neurodegenerative disease, affecting approximately 1% of the population over 60 years of age. It is a progressive disorder of the central nervous system, characterized clinically by tremors, bradykinesia, stiffness and postural instability.[1] Although the diagnosis is based on motor symptoms, non-motor symptoms and psychiatric disorders, such as depression, are very prevalent.[2,3] Among the available drug treatments, levodopa and dopaminergic agonists are generally safe and effective.[1] However, some patients may exhibit motor symptoms that are refractory to drug treatment, and for these cases neurosurgical treatment can be indicated. One such treatment is deep brain stimulation (DBS), which consists of implanting

electrodes, usually in the subthalamic nucleus or the internal globus pallidus.[4,5]

Patients with chronic neuropsychiatric diseases are likely to suffer stigma during their lifetime. Stigma arises when a person has a characteristic often considered negative by society. This negative stereotype can lead to suffering from prejudice and discrimination. When these negative public attitudes, known as social stigma, are believed by the person with an unfavorable condition, "self-stigma" occurs, which is usually associated with decreased self-esteem and self-efficacy.[6,7] Diseases such as PD and depression are often accompanied by stigma.[8-12] A study evaluating public opinion about PD revealed that more than half of the affected individuals would try not to reveal their diagnosis if they had the disease.[9] Another qualitative study found that stigma from

PD was prevalent in all its participants, who reported feelings of isolation and attempting to mask their symptoms.[10] Stigma from neuropsychiatric diseases has various harmful consequences, including a delayed search for medical help, diagnosis and treatment, lower quality of life, social isolation, non-adherence to treatment and increased suicide rates.[13-16] Thus, studying variables associated with stigma might help health professionals find ways to intervene and reduce it.

The objective of this study was to identify variables associated with self-stigma in PD patients who are candidates for DBS, a population that presents motor symptoms that are generally more severe or refractory to drug treatment. Our hypothesis was that depressive symptoms would be associated with increased stigma in PD patients, regardless of the intensity of motor symptoms.

Methods

This cross-sectional study was conducted at the Hospital Governador Celso Ramos in Florianópolis, Santa Catarina state, Brazil, from February 2014 to September 2015.

Participants

Patients diagnosed with PD according to the clinical criteria of the Queen Square Brain Bank[17] who were candidates for DBS participated in the study. Participants were followed up at the Movement Disorders Outpatient Clinic at the Hospital Governador Celso Ramos and underwent neurological and neurosurgical screening for DBS, as well as psychiatric and quality of life assessment. The exclusion criterion was clinical diagnosis of dementia according to neurological assessment.

Quality of life assessment

The 39-item Parkinson's Disease Questionnaire (PDQ-39)[18] was used to assess quality of life. The PDQ-39 is a validated and widely used scale for assessing health-related quality of life in PD patients.[19] This scale has eight domains (Mobility, Activities of daily living [ADL], Emotional well-being, Stigma, Social support, Cognition, Communication and Bodily discomfort). The scores range from 0 to 100, with higher scores indicating poorer quality of life. The Stigma domain consists of the following questions: "Due to Parkinson's Disease, how many times during the past month have you: 1) Felt you had to hide the disease from other people? 2) Avoided situations that involved eating or drinking in public? 3) Felt embarrassed in public? 4) Felt concerned about other people's reactions to you?" Each question is scored from zero (never) to four (always). These questions go hand in hand with the concept of self-stigma, that is, when the patient agrees with, adheres to and self-applies stereotypes, reducing self-efficacy and self-esteem.[20]

Neurological evaluation

PD motor symptoms were assessed using the Movement Disorder Society-sponsored revision of the Unified Parkinson's Disease Rating Scale (MDS-UPDRS III), with all patients on their regular medication.[21] The disease stage was evaluated using the Hoehn & Yahr[22] scale.

Psychiatric evaluation

The diagnostic evaluation was performed according to the Structured Clinical Interview for Diagnostic and Statistical Manual of Mental Disorders, 4th edition, Axis I Disorders (SCID-I).[23] Anxiety and depression symptoms were quantified with the Hospital Anxiety and Depression Scale (HADS),[24] an instrument used to evaluate depression and anxiety in patients with general medical conditions, including PD. All questionnaires had been previously translated into and validated for Portuguese. Due to the low education level of the sample, the HADS and PDQ-39 scales were not self-administered. The patients' general medical condition was assessed by asking whether they had been diagnosed with any disease according to a medical evaluation.

Based on the literature and the investigators' clinical experience, the independent variables included in the analysis were age,[25] disease duration, the presence of a general medical condition,[26] MDS-UPDRS III score,[27] HADS depression subscale score[25] and the PDQ-39 domains of mobility, ADL[27] and emotional well-being. The outcome variable was the PDQ-39 Stigma domain score.

Data analysis

Continuous variables were described as means and standard deviations (SD) or median and interquartile range according to the parametric or non-parametric data distribution, respectively. Categorical variables were described as absolute numbers and frequencies.

The Kolmogorov-Smirnov test was used to test the null hypothesis of parametric distribution in the Stigma domain score. The association between each of the independent variables and the outcome was analyzed using simple linear regression. Independent variables associated with the outcome that had a p-value less than or equal to 0.20 were included in a multiple linear regression model. In the final model, p-values less than 0.05 were considered statistically significant.

Ethics statement

This study is part of a research project approved by the medical ethics committees of Hospital Governador Celso Ramos and the Universidade Federal de Santa Catarina and follows the guidelines of the Code of Ethics of the World Medical Association (Declaration of Helsinki).[28] An informed consent form was signed by all participants.

Results

In the study period, 54 patients whose neurological examinations indicated DBS treatment underwent psychiatric evaluation. The sample was mostly male (63%), married (70.4%) and had a mean age of 58±7.4 (SD) years. Half of the sample had less than four years of education.

The mean duration of the disease was 14.1 years±6.2 (SD) years (Table 1).

Approximately 15% of the sample was diagnosed with a major depressive episode, and more than 40% had some general medical condition (Table 1), with systemic arterial hypertension, dyslipidemia and diabetes mellitus being the most prevalent (22%, 11% and 9.3%, respectively) (Table 2).

Table 1 General characteristics of Parkinson's disease patients indicated for deep brain stimulation

Variables	n (%)
Sex	
Female	20 (37)
Male	34 (63)
Age in years, mean (SD)	58.2 (7.4)
Years of education*	
More than 4	26 (50)
Less than 4	26 (50)
Marital status	
Married	38 (70.4)
Single	16 (29.6)
Disease duration in years, mean (SD)	14.1 (6.2)
MDS-UPDRS III score, mean (SD)	27.1 (14)
Hoehn & Yahr stage, median (IQR)	3 (2/3)
Major depressive disorder*	
Yes	8 (15.4)
No	44 (84.6)
HADS score, mean (SD)	11.6 (6.6)
HADS Depression score, mean (SD)	5.5 (3.8)
Medical condition (non-psychiatric)	
Yes	24 (44.4)
No	30 (55.6)
PDQ-39 domain scores, mean (SD)	
Stigma	47.62 (31.3)
Mobility	59.81 (24.5)
Activities of daily living (ADL)	65.07 (24.8)
Emotional well-being	41.5 (25.5)

Data presented as n (%), unless otherwise specified.
HADS = Hospital Anxiety and Depression Scale; IQR = interquartile range; MDD = major depressive disorder; MDS-UPDRS III = Movement Disorder Society-sponsored revision of the Unified Parkinson's Disease Rating Scale; PDQ-39 = 39-item Parkinson's Disease Questionnaire; SD = standard deviation.
* Two participants not evaluated.

According to the Kolmogorov-Smirnov normality test, the distribution of stigma scores failed to reject the null hypothesis of normal distribution (p = 0.15). In the univariate analysis, scores in the ADL and emotional well-being domains were significantly associated with the Stigma domain score. HADS depression subscale scores, Mobility domain scores and age showed association trends (Table 3). In the multiple regression analysis (Table 4), only the ADL domain score was independently associated with the outcome (for each increase of one unit in the ADL subdomain score, there was an increase of 0.42 in the Stigma domain). As already mentioned, for both the ADL and stigma domains, higher scores indicate poorer performance. The full model accounted for 15% of the variance in Stigma domain (p = 0.03). The regression standardized residual from the multiple linear regression analysis followed normal distribution according to the Kolmogorov-Smirnov normality test (p = 0.58). We conducted multicollinearity analysis in the regression model to ensure that the contribution of each aspect of quality of life was independent. The fact that the variance inflation factor was below 2.5 and the condition index was lower than 30 indicates weak multicollinearity.[29,30]

Discussion

In this study, greater difficulty in ADL was independently associated with higher self-stigma. In contrast with our hypothesis and other studies, depressive symptoms were not associated with greater stigma in a multiple linear regression model.

In a study of 150 individuals with PD,[3] symptoms of apathy and depression were significantly associated with stigma. Another study showed that stigma was a determinant of depression, which was a predictor of the quality of life.[31] Ma et al.,[32] in a study of PD patients, found that those with more depressive symptoms reported more stigma, especially self-stigma, which appears to be of greater and more direct importance in quality of life than social stigma. Our sample likely diverged from these results due to its relatively low level of depressive symptoms, since approximately 70% of the patients scored up to nine on the HADS depression subscale, whose suggested cut-off for a major depressive episode is 10/11.[33] In addition, the PD patient profile in our study differed from most studies, i.e., it was more symptomatic and refractory to drug treatment.

The ADL domain shows how individuals with PD see their own limitations in their daily lives. In our study, this perception was significantly associated with self-stigma.

Table 2 Medical conditions reported by Parkinson's disease patients indicated for deep brain stimulation

Medical condition	n (%)	Medical condition	n (%)
High blood pressure	12 (22)	Backache	2 (3.7)
Dyslipidemia	6 (11)	Arrhythmia	2 (3.7)
Diabetes mellitus II	5 (9.3)	Asthma	1 (2)
Ischemic heart disease	2 (3.7)	Osteoporosis	1 (2)
Herniated disc	2 (3.7)	Hypothyroidism	1 (2)

Six patients (11% of the total sample) reported two or more medical conditions.

Table 3 Simple linear regression analysis between independent variables and the Stigma domain of the 39-item Parkinson's Disease Questionnaire (PDQ-39) scale in Parkinson's disease patients indicated for deep brain stimulation

Stigma domain	R	R^2	Coefficient β (95%CI)	p-value
HADS depression scale	0.25	0.06	2.05 (-0.17 to 4.28)	0.07
MDS-UPDRS III	0.004	0.000	0.01 (-0.69 to 0.70)	0.98
Disease duration	0.08	0.01	0.43 (-1.03 to 1.89)	0.56
Age	0.25	0.06	-1.05 (-2.25 to 0.14)	0.08
Medical condition*	0.02	0.001	-1.44 (-18.93 to 16.04)	0.87
Mobility domain	0.26	0.07	0.33 (-0.01 to 0.68)	0.06
Activities of daily living	0.34	0.12	0.42 (0.09 to 0.76)	0.01
Emotional well-being domain	0.31	0.09	0.37 (0.04 to 0.70)	0.03

* Any other medical condition reported by the patient during the psychiatric evaluation.
95%CI = 95% confidence interval; HADS = Hospital Anxiety and Depression Scale; MDS-UPDRS III = Movement Disorder Society-sponsored revision of the Unified Parkinson's Disease Rating Scale.

Table 4 Multiple linear regression model showing variables independently associated with the Stigma domain of the 39-item Parkinson's Disease Questionnaire (PDQ-39) scale

Variables	R	Adjusted R^2	F	Coefficient β (95%CI)	p-value
Stigma domain	0.49	0.15	2.72		
HADS depression scale				0.97 (-1.44 to 3.37)	0.42
Age				-0.96 (-2.10 to 0.16)	0.09
Mobility domain				-0.10 (-0.56 to 0.35)	0.65
Activities of daily living				0.42 (0.003 to 0.83)	0.048
Emotional well-being domain				0.28 (-0.08 to 0.64)	0.12

95%CI = 95% confidence interval; HADS = Hospital Anxiety and Depression Scale.

Although causality cannot be determined from cross-sectional studies, the results suggest that when patients perceive greater difficulty in their daily activities, self-depreciation could increase. Such a relationship was also found by Ma et al.[32] We found no association between stigma and scoring on the MDS-UPDRS III scale, which evaluates motor difficulties objectively using a third evaluator, which demonstrates the importance of patient self-perception. Thus, although motor symptoms, which had been objectively assessed by a neurologist, were not associated with patient self-stigma, patient perception of difficulties with daily activities was associated with self-stigma, independently of depressive symptoms or other characteristics of the disease.

The findings of this study may not be comparable to those of others due to differences in methodology, criteria and definitions. Moreover, the samples could be differentiated at a sociocultural level. Stigma is inherent in sociocultural interference; populations interpret the symptoms of each disease in different ways (i.e., diverse beliefs about family inheritance, neurobiology, social factors and even personality traits),[6,8,9] leading to different forms and degrees of what could be considered stigmatization. Our sample also differed from a number of studies due to our sample's lower education and longer disease duration.[3,31,32]

Non-pharmacological and non-surgical interventions can be effective in treating the physical and psychological symptoms of PD patients. In a case control study[34] in which a protocol of easily executed physical activities with low social and economic cost was performed, there was improvement in ADL performance in both PD and Alzheimer's patients. Other studies incorporating dance and martial arts,[35,36] such as Tai Chi, have found

improvement in motor symptoms, muscle strength, balance, some aspects of cognition and ADL, which could contribute to increase feelings of independence despite the disease. In another study,[9] more than 50% of the population reported substantial concern about becoming dependent on others if they had PD. Relatively simple environmental interventions can benefit patients with PD in the sense of understanding and facing their true limitations, socializing in similar groups and increasing their self-satisfaction and independence in ADL, which could help reduce self-stigma. Measures to combat stigma are international research priorities.[37]

Among the limitations of this study, it is important to emphasize its cross-sectional design, which does not allow for inferences about causal relationships between independent variables and outcomes. In addition, the sample consisted of more severely affected patients, which could limit generalization of the findings to other populations. Finally, since the measures of ADL and stigma are both domains of the PDQ-39, multicollinearity could be an issue, although the analysis suggested that the contribution of each aspect to quality of life was independent. Further studies with other validated instruments for measuring activities of daily living and stigma are necessary.

Difficulties in ADL were associated with greater stigma in patients with PD refractory to drug treatment, regardless of depressive symptoms or objectively measured motor symptoms. Since self-stigma is associated with impairments, such as treatment noncompliance and even suicide risk,[15] environmental interventions that facilitate the day-to-day lives of patients could help them cope better with the limitations of their disease, possibly reducing self-deprecating feelings that could contribute to worse prognosis.

Acknowledgements

Disclosure

The authors report no conflicts of interest.

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