



Independence of Coping Styles With the Patient–Doctor Relationship and Shared Decision-Making in People With Parkinson’s Disease

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Abstract

Introduction: Coping styles have a mediating effect on several clinical outcomes. The patient–doctor relationship and the patient’s role in decision-making process might be influenced by the way the patient reacts to certain stressors or problems due to the evolution of their disease. **Objective:** To assess the role of coping strategies on the patient–doctor relationship and the patient’s role in decision-making in a group of people with Parkinson’s disease (PD). **Methods:** A cross-sectional study was carried out. The Coping Style Questionnaire (CSQ-40), the 9-item Patient–Doctor Relationship Questionnaire (PDRQ-9), and the 9-item Shared Decision-Making Questionnaire (SDM-Q-9) were applied. **Results:** A total of 36 women and 64 men with PD were included. The predominant coping style in women was rational. In men, the detachment style was more frequent. The SDM-Q-9 mean score was 33.2 ± 11.2 (transformed median score of 80). The PDRQ-9 average score was 2.9 ± 1 (sum score of 26.1 ± 8.7). No association was found between the CSQ-40 with the PDRQ-9 or SDM-Q-9. On the other hand, the PDRQ-9 mean score and the transformed SDM-Q-9 score highly correlated ($r = 0.62, P < .001$). **Conclusion:** Patient–doctor relationship and shared decision-making are independent of the coping style in people with PD.

Keywords

coping, patient–doctor relationship, decision-making, Parkinson’s disease

Introduction

Parkinson’s disease (PD) is the second most common chronic progressive neurodegenerative disorder. Parkinson’s disease has an insidious onset characterized by the presence of both nonmotor and motor symptoms, such as bradykinesia, rest tremor, rigidity, and postural disturbances. Currently, only symptomatic treatment is available. If not adequately treated, these symptoms have a major role in overall disability, decreasing the quality of life (1) and affecting almost all aspects of their daily living (2).

Coping is described as a series of strategies patients create to manage a certain stressor or problems derived from their condition, this simplifies the process of adaptation of living with the disease (3) and might be influenced by the way the patient relates with their physician (4). It has been suggested that patients with PD are more introverted apprehensive, impulsive, restless, and cautious when

compared to healthy patients. Patients may show lower levels of openness, extraversion, and agreeableness that can influence the type of coping strategies used to overcome stressful events (5).

Roger et al described 4 coping styles: emotional, avoidance, rational, and detachment (6). Emotional coping style involves negative emotional reactions. For example, anger

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or sadness, toward a problem or stressor. On the other hand, rational coping style includes behaviors oriented to solving problems, seeking solutions, and cognitive reevaluation of the problem. Detachment coping style refers to ideas or feelings of disconnection the person experiences toward the actual situation. Finally, avoidance coping style is present when a person has no strategy to deal with the problem and waits for it to spontaneously resolve itself.

Since the introduction of levodopa in the 1960s, quality of life has improved and mortality rates have considerably decreased for people with Parkinson's disease (PwP) (7), which means the relationship between patients and their doctors can last for decades. A recent survey carried out by the European Parkinson's Disease Association found out that a better quality of life is often associated with higher levels of satisfaction with attention and care (8).

Communication is fundamental to the shared decision-making process, as well as achieving patient engagement (9). It is essential to know what is important to patients; their desires, expectations, and attitude toward getting involved in the decision-making process (10). Doctors often misjudge a patient desire for involvement in decision-making and let them play a more passive role (9); however, it has been reported that patients are more likely to be compliant when they are involved in the decision process (11).

Available data on coping styles in PwP come from a series of qualitative and quantitative studies aimed to identify the most common coping style among this population (4). In other diseases such as cancer, it has been shown that the doctor must gain insight into the patient's way of coping in order to adequately influence the coping process (12,13). Also, coping styles are involved in the initial process of decision-making including identification of the health threat, presentation of choice, and interpretation of options (14).

Understanding of the role of coping strategies on the patient–doctor relationship and patient's role in the decision-making process in the context of PD has not been fully explored. The aim of the study is to assess the relation of coping strategies on the patient–doctor relationship and the patient's role in decision-making perception in a group of persons with PD.

Methods

A cross-sectional study including patients with PD attending the Parkinson's disease Awareness Month activities that were celebrated at the National Institute of Neurology and Neurosurgery (NINN) in Mexico City on April 2, 2019, was carried out. Participants considered for this study were previously diagnosed with PD by a movement disorder specialist or neurologist. All patients with PD were invited to participate, regardless of the hospital in which they receive their care. Those who voluntarily agreed to participate were given a written full explanation of the study and signed an informed consent form. A study waiver was granted by the local Ethics Committee since anonymity was guaranteed as

no personally identifiable information was collected, and results would not be shared with their doctors.

Anonymous questionnaires included sociodemographic variables such as gender, date of birth, current marital, employment status, maximum educational level, the state they reside in, and if they have social security. Finally, a series of questions regarding PD care were asked, including the year of symptoms onset, year of diagnosis, an estimated number of medical appointments with their specialized neurologist throughout the last year, and whether they agreed that the number of appointments given sufficed.

Afterward, 3 different instruments to assess coping style, patient–doctor relationship, and shared decision-making were applied. These instruments included the validated Spanish versions and in all cases the questionnaires were self-applied.

The Coping Style Questionnaire (CSQ-40) is comprised of 4 factors: rational coping, detached coping, emotional coping, and avoidance coping. The CSQ-40 has 40 items, each with 4 different response options (never = 0, sometimes = 1, often = 2, always = 3). Participants are instructed to think about any problem or complicated situation that was caused or worsened by their disease and how they would usually react to it. Each subscale is summed to give a score for each of the 4 coping styles; the highest score within the categories denotes the most predominant coping style. Both rational and detachment styles are considered positively related and express a sense of adaptation toward the stressor. Emotional and avoidance styles positively correlate but reflect a lack of adaptation facing the problem or stressor, which means they are negative or maladaptive coping styles. A Spanish version of the CSQ-40 has been validated with acceptable internal consistency by Guarino et al (15).

The Patient–Doctor Relationship Questionnaire (PDRQ-9) evaluates the patient–doctor relationship from the perspective of patients by assessing the overall quality of the therapeutic alliance (16). The PDRQ-9 was designed for use in primary care settings but also can discriminate between respondents from a specialty clinics and primary care clinics. The PDRQ-9 is comprised of 9 questions on a 5-point Likert scale (from “1 = not at all appropriate” to “5 = totally appropriate”). The PDRQ-9 can be reported as either a mean score or a total sum score. A high mean score corresponds with a strong therapeutic alliance. The Spanish version of the PDRQ-9 has been validated, showing to be internally consistent and be comprised of a single-relationship factor (17).

The 9-item Shared Decision-Making Questionnaire—patient version (SDM-Q-9) is a brief and easy-to-administer patient-reported tool. The SDM-Q-9 uses a 6-point Likert scale as response (“completely disagree” to “completely agree”), with a score ranging between 0 and 45, with 0 indicating the lowest of perceived shared decision-making and 45 indicating the highest (18). Also, the total score is multiplied by 20/9 to provide a transformed range from 0 to 100 (highest extent of SDM) as recommended. Items were also summarized in 2 categories,

Table 1. Demographic Characteristics of the Study Sample.

Variable	Non-NINN, n = 45	NINN, n = 55	P
Men	30 (66.7%)	34 (61.8%)	.62
Age	66.3 ± 11.4	62.9 ± 11.6	.15
Years of education	12.4 ± 5.5	10.9 ± 5.5	.19
Marital status			
Married/free union	30 (66.7%)	41 (74.5%)	.39
Single/widowed/divorced	15 (33.3%)	14 (25.5%)	.39
Employment status			
Working	9 (20%)	13 (23.6%)	.66
Unemployed	11 (24.4%)	20 (36.4%)	.20
Retired	14 (31.1%)	4 (7.3%)	.002
House wife/man	11 (24.4%)	18 (32.7%)	.36
Public health insurance			
Yes	31 (68.9%)	26 (47.3%)	.03
No	14 (31.1%)	29 (52.7%)	.03
Disease duration	8.7 ± 5.9	9.4 ± 6.3	.57
Consultations in the last year	3 ± 2	4.2 ± 3.2	.03
PDRQ-9	2.7 ± 1.1	3.1 ± 0.9	.08
SDM-Q-9	68.3 ± 27.7	77.8 ± 22	.07

Abbreviations: NINN, National Institute of Neurology and Neurosurgery; PDRQ-9, 9-item Patient-Doctor Relationship Questionnaire; SDM-Q-9, 9-item Shared Decision-Making Questionnaire.

“disagree” (responses 0-2) and “agree” (responses 3-5) as suggested by De las Cuevas et al (19). The Spanish version of the scale has adequate reliability and internal consistency (20), and a Latin American Spanish version has also been recently validated (21). For both the PDRQ-9 and the SDM-Q-9, participants were asked to think about their most recent medical appointment with their specialized neurologist as a reference for the rating.

Statistical Analysis

Data were expressed in terms of frequencies, means, and standard deviations. Distribution of the variable was assessed using the Shapiro-Wilk test. Correlation was assessed using Pearson or Spearman correlation coefficients as needed. Correlations were classified as strong ($r \geq 0.60$), moderate ($r = 0.40-0.59$), and weak ($r = 0.2-0.39$). For comparison between groups, continuous variables were analyzed using a *t* test or its nonparametric equivalent as required. Categorical variables were assessed using the χ^2 test. A *P* value of $<.05$ was considered statistically significant. Statistical analyses were performed using SPSS, version 17 (SPSS, Inc, Chicago, Illinois).

Results

A total of 100 PwP were included (36 women and 64 men). The mean age was 64.4 ± 11.6 years; the mean year of education was 11.6 ± 5.5 . Regarding their marital status, a total of 64 (64%) PwP were married and 60 (60%) had access to social security. The mean duration of the disease was 9.1 ± 6.1 years. A total of 55 PwP were patients of the

NINN, while the remaining received medical attention elsewhere. Table 1 presents the comparison of the main demographic characteristics between PwP treated at the NINN and those seen elsewhere. This comparison was carried out because the NINN is a tertiary referral center, while the other centers provide primary or secondary care and some differences in number of visits and demographics might be expected.

Regarding the CSQ-40, rational coping and detached coping scored the highest (mean score of 19.1 ± 7.1 and 17.7 ± 6.3 , respectively). Emotional coping and avoidance coping scored the lowest (11.7 ± 7.2 and 7.3 ± 3.9 , respectively). Of all 4 coping style scales, 51% of PwP scored highest on rational coping, 30% on detached coping, 16% on emotional coping, and 0% on avoidance coping.

The SDM-Q-9 mean score was 33.2 ± 11.2 and the transformed median score was 80 (interquartile range: 35.5). Overall, 81.7% of the PwP agree to some degree that they were part of the decision-making process. Table 2 presents the individual data for each of the SDM-Q-9 items.

Finally, the PDRQ-9 average score was 2.9 ± 1 (sum score of 26.1 ± 8.7). Descriptive data on each item of the PDRQ-9 is indicated in Table 3.

When comparing by gender, no statistical significant differences were found between women and men for the PDRQ-9 (3 ± 0.9 vs 2.9 ± 1 , $P = .70$), SDM-Q-9 (33.8 ± 11.2 vs 32.8 ± 11.3 , $P = .72$), or transformed SDM-Q-9 (75 ± 25 vs 73 ± 25.1 , $P = .72$). Rational coping scores were higher in men in comparison to women (20.6 ± 7 vs 16.4 ± 6.5 , $P = .005$). Consequently, differences were found in the coping style with rational coping being more common in men (63.5% vs 32.4%, $P = .003$) and detached coping in women (44.1% vs 23.8%, $P = .04$). No differences were found for emotional coping ($P = .15$). There were no differences in the PDRQ-9, SDM-Q-9, and CSQ-40 according to their marital status, social security availability, or their primary health center. No statistically significant correlation was found with age, age at onset, or years of education. Finally, no correlation was found between any of the CSQ-40 factors and the PDRQ-9 or the SDM-Q-9. A significant correlation was found between PDRQ-9 mean score and the transformed SDM-Q-9 score ($r = 0.62$, $P < .001$).

Discussion

Throughout the progression of PD, in addition to the wide variety of symptoms, patients are frequently exposed to stress as they experience new impairments and disabilities, urging them to look for new techniques to cope with the disease (21). Traditionally, coping methods have been described as a dichotomy, either oriented to emotional-based or rational strategies. Rational and detachment styles are considered positively related and express a sense of adaptation toward the stressor. Emotional and avoidance styles positively correlate as well, but they reflect a lack of adaptation facing the problem or stressor, which means they

Table 2. Central Tendency and Dispersion Measures of the Items in the 9-Item Shared Decision-Making Questionnaire—Patient Version.

	Agree (%)	Disagree (%)	Mean	Standard Deviation	Item-Total Correlation ^a
My doctor helped me understand all the information	91.2	8.8	2.77	1.06	0.903
My doctor wanted to know exactly how I want to be involved in making the decision	85.6	15.4	2.68	1.24	0.801
My doctor made clear that a decision needs to be made	84.6	15.4	2.96	1.07	0.890
My doctor told me that there are different options for treating my medical condition	82.4	17.6	3.16	1.06	0.823
My doctor precisely explained the advantages and disadvantages of the treatment options	80.2	19.8	2.86	1.12	0.892
My doctor and I thoroughly weighed the different treatment options	80.2	19.8	2.86	1.18	0.859
My doctor and I reached an agreement on how to proceed	80.2	19.8	2.92	1.14	0.882
My doctor asked me which treatment option I prefer	75.8	24.2	2.97	1.12	0.845
My doctor and I selected a treatment option together	74.7	25.3	2.88	1.16	0.814

^aP < .001.

Table 3. Central Tendency and Dispersion Measures of the Items in the Patient–Doctor Relationship Questionnaire.

	Theoretical Range ^a	Mean	Standard Deviation	Item-Total Correlation ^b
My doctor helps me	1-5	2.96	1.07	0.890
My doctor has enough time for me	1-5	2.68	1.24	0.801
I trust my doctor	1-5	3.16	1.06	0.823
My doctor understands me	1-5	2.86	1.12	0.892
My doctor is dedicated to help me	1-5	2.77	1.06	0.903
My doctor and I agree on the nature of my medical symptoms	1-5	2.97	1.12	0.845
I can talk to my doctor	1-5	2.86	1.18	0.859
I feel content with my doctor's treatment	1-5	2.88	1.16	0.814
I find my doctor easily accessible	1-5	2.92	1.14	0.882

^a1 = "not at all appropriate"; 3 = "appropriate"; to 5 = "totally appropriate."

^bP < .001.

are negative or maladaptive coping styles (15). In this study, rational coping followed by detached coping were the more common coping styles, also known as adaptive. Coping style is only related to gender, with rational coping being more prevalent in men and detached coping in women.

The patient–doctor relationship plays a fundamental role in the daily practice of medicine as it involves 2-way communication between the physician and the patient, and refers to a relationship of mutual respect, trust, and confidence (22). It is not strictly necessary for doctors to know almost every social, cultural, or religious aspect of their patients' lives. However, getting to know such differences strengthens the relationship with their patients and even their families (23) and improves quality of care (24). This has a small but statistically significant effect on health outcomes (25, 26). Montanaro et al studied the patient–doctor relationship in 24 PwP requiring advanced treatment. The mean PDRQ-9 sum score was 37.3 ± 7.3 (27). Our study sample scored significantly lower; this might be due to the clinical characteristics of the PwP. Disease severity was not objectively assessed with rater-administered scales, but heterogeneity was present ranging from mild to moderate stages. To our knowledge, no other study has used the PDRQ-9 in PwP and further studies are needed including subjects in early as well as late stages of the disease.

In our sample, no association was found between the coping style and the patient–doctor relationship. For study purposes, it was hypothesized a priority that positive coping styles would result in a better patient–doctor relationship, while maladaptive coping styles would harm the relationship. One possible explanation for the lack of association is that the doctor might have identified how the patient copes with the disease and forged the relationship on it. In other words, it is possible that the doctor adapted to the patient independently of the coping style. It is interesting that currently there are no validated questionnaires or scales aimed to assess the perceived patient–doctor relationship from the doctor's perspective. Similarly, coping style questionnaires have been designed for specific situations such as diseases or social situations, but no specific tool for assessing how doctors cope with the disease of their patients is available to the best of our knowledge. This is undoubtedly an area of opportunity for further studies.

Finally, to understand the relationship that exists between health-care professionals, patients, and even health-care systems, a patient-centered care model must be adopted, and patients should be considered as active agents in their disease and as the ones capable of modifying their own health (19). Shared decision-making process guarantees that both doctor and patient reach agreements. This way, both of them

play an active role in the process and are equally responsible for the decisions made. In this process, they evaluate internal and external information and make the most adequate decision based on their knowledge and own experiences (28). A study carried out in the Netherlands in 2016 found out that 45% of 192 PwP preferred having an active role in the treatment decision-making process, while almost 11% of them preferred a more passive role (10). Nijhuis et al studied shared decision-making in 121 PwP who started advanced PD treatment; 93% reported that they preferred to be actively involved in the decision-making process (29). In addition, one of the main facilitators of SDM was the patient–doctor relationship.

Interestingly, SDM-Q-9 has been used more commonly in the oncology setting, and data on neurological diseases have not been published. A systematic review on the use of SDM-Q-9 reported a mean sum scores ranging from 42 to 75 (30). In our study, the mean score was 33.2, but as mentioned before, no data are available for comparison in neurological disease setting.

De las Cuevas et al analyzed the SDM-Q-9 total score between patients from a primary care setting in comparison to those in a psychiatric outpatient clinic. Although no differences in the total score were found, patients in a psychiatric setting had a distinct pattern characterized with higher agreement at initial steps (need of a decision to be made and equality) and disagreement in later steps of the process (negotiation, shared decision, follow-up) (31). In our PwP sample, percentage of agreement remained stable throughout the different items of the SDM-Q-9. This is interesting, given that PD is comprised of a wide range of neuropsychiatric symptoms.

No association was found between coping styles and shared decision-making. The working hypothesis stated that positive coping styles would result in a better shared decision-making. Since patient–doctor relationship and shared decision-making scales showed a high correlation, the lack of association might be expected. Although patient–doctor relationships and shared decision-making appear to be dependent on each other, we cannot rule out other factors that were not taken into account in the study, such as health literacy and knowledge of the disease.

The study has several limitations. First of all, a selection bias may be present. It can be argued that PwP attending patient-oriented meetings have more interest in dealing with the disease and might have a better relationship with their doctors. Rational coping is a task-oriented response and may be expected in people attending this type of event. Second, data regarding the attending doctor were not collected. Although no statistical difference was found, PwP attending other hospital centers tend to score lower in the PDRQ-9 and SDM-Q-9. On this matter, we believe that full anonymity reduced the risk of response bias to the PDRQ-9 and SDM-Q-9. It must be pointed out that a physician version of the SDM-Q-9 (SDM-Q-Doc) is available. However, due to the study design and setting, it was not used. Reporting bias was

also possible since the SDM-Q-9 and PDRQ-9 reflect only the experience during the last medical visit and not necessarily the experience throughout the course of the disease. Also, no clinical instruments for PD evaluation were applied. On this matter, it is important to mention that the objective of the study was not to address the association between CSQ-40, PDRQ-9, and SDM-Q-9 and the severity of the disease or the adherence to treatment. Lastly, whether or not our findings might apply to people with different sociocultural backgrounds (external validity) warrants further study.

Conclusion

In PwP, the most common coping styles are rational coping and detached coping which are considered adaptive and positive. No association between coping style and any of the measures of patient–doctor relationship or shared decision-making was found. The PDRQ-9 and SDM-Q-9 scores were acceptable but lower in comparison to other diseases. More studies assessing patient–doctor relationship and shared decision-making in the context of PD are needed. Qualitative studies incorporating a focus group interview assessing other factors such as patient expectations, health literacy, disease knowledge, self-care behaviors, and family carer involvement may shed some more light on this complex interaction between patient and doctor.

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