

# Impact of Coronavirus Disease 2019 Pandemic on Parkinson's Disease: A Cross-Sectional Survey of 568 Spanish Patients

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**ABSTRACT: Background:** The aim of this study was to know the impact of the coronavirus disease 2019 (COVID-19) pandemic on Spanish patients with Parkinson's disease (PD).

**Methods:** This is a descriptive, observational, cross-sectional study. An anonymous online survey with 95 questions was distributed among patients. Responses were collected from 11 May 2020 to 20 July 2020.

**Results:** Of a total of 570 questionnaires received, 568 (99.6%) were considered valid for the analysis (mean age, 63.5 ± 12.5 years; 53% females). A total of 553 patients (97.4%) were aware of the COVID-19 pandemic and 68.8% were concerned about it; 95.6% took preventive measures. A total of 484 patients (85.2%) had no contact with cases of COVID-19, and only 15 (2.6%) had confirmed COVID-19. Although up to 72.7% remained active during confinement, 65.7% perceived a worsening of their symptoms.

**Conclusions:** Spanish patients with PD perceived the COVID-19 pandemic with concern and responsibility. More than half experienced worsening of their symptoms during confinement. © 2020 International Parkinson and Movement Disorder Society

**Key Words:** confinement; COVID-19; impact; pandemic; Parkinson's disease

The coronavirus disease 2019 (COVID-19) pandemic has resulted in unprecedented disruptions involving every aspect of life across the globe.<sup>1</sup> Governments have taken several measures, such as people lockdown, quarantining infected individuals and their family members, canceling public transportation, exit controls, travel and contact restrictions, curfews, school closures, and requiring people to wear mouth and nose masks.<sup>2–4</sup>

The healthcare sector has undergone dramatic changes as well to cope with the current needs, with the major impact of this social and health crisis on patients with chronic diseases.<sup>5</sup> Although there is no evidence that patients with Parkinson's disease (PD) have a higher risk for contracting COVID-19 or have worse outcomes,<sup>6,7</sup> the impact of stress, self-isolation, depression, and anxiety, as well as the consequences of the health system restrictions and prolonged immobility because of the lockdown may have several short-term and long-term adverse consequences for people with PD, such as worsening of motor function and stress-related psychiatric symptoms, such as anxiety and depressive mood.<sup>8–12</sup>

The main objective of this study was to know how the COVID-19 pandemic has affected Spanish patients with PD based on data from a sample of patients interviewed through an anonymous and voluntary online survey.

## Patients and Methods

This is a descriptive, observational, cross-sectional study with a type-anonymous survey of patients with PD. A survey with 95 questions structured in three parts was developed. Part I (PD) included questions 1–61 related to the following categories: sociodemographic variables, variables related to PD, variables related to comorbidities, lifestyle, treatment, quality of life, and independence. Part II (COVID-19) included questions 62–89 that focused on knowledge about the COVID-19 crisis, COVID-19, and impact of the COVID-19 pandemic. Part III (caregiver) included questions 90–95 about the role and burden of the caregiver. In addition, the participants had a free field to leave comments at the end of the survey. The time it took to answer the survey was between 10 and 15 minutes.

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The survey was in Spanish in electronic format. Participation was voluntary and anonymous, so that anyone who deemed it appropriate could participate. In the questionnaire it was clear that the participant must have PD or be the caregiver or a family member of a patient with PD who was currently alive or who had died during the pandemic (since March 2020), with the data collected referring to their sick family member (except Part III). The study was launched on 11 May 2020 and disseminated on social networks and different media. Responses were collected from 11 May 2020 to 20 July 2020. It was approved by the regional ethics committee from Galicia. Data were processed using SPSS 20.0 (Armonk, NY) for Windows. The *P* value was considered significant at  $<0.05$ .

## Results

Of a total of 570 questionnaires received, 568 (99.6%) were considered valid for the analysis. A total of 327 (57.6%) surveys were answered by patients with PD, 238 (41.9%) by caregivers, and 3 (0.5%) by a relative of a patient with PD who had died. Responses from 49 provinces in Spain were received, with 46.7% during the first 3 days. Mean age of patients was  $63.5 \pm 12.5$  years (range, 30–92 years), and 53% ( $n = 301$ ) were female. Sociodemographic data are shown in Table 1.

Mean disease duration was  $8.4 \pm 5.6$  (range, 1–30) years. More than half of the patients suffered from tremor, rigidity, falls, motor fluctuations, dyskinesias, anxiety, depression, and pain, and about one in three presented with cognitive problems and behavioral disorders (Table 2, all patients). Symptoms related to PD and comorbidities are listed in Table 2.

Table S1 shows the data related to COVID-19. A total of 553 patients (97.4%) were aware of the COVID-19 pandemic, and 68.8% were concerned about it; 95.6% took preventive measures: 86.8% frequent hand washing, 86.6% wearing a mask, 86.3% rigorous confinement, 80.1% social distancing, and 41.4% use of gloves. A total of 484 patients (85.2%) had no contact with cases of COVID-19, and only 15 (2.6%) had confirmed COVID-19. Out of 15 patients who had COVID-19, 5 (33.3%) were hospitalized (1 in the intensive care unit [ICU]), but none of them died. Although up to 72.7% remained active during confinement, 65.7% perceived a worsening of their symptoms: bradykinesia 47.7%, sleep problems 41.4%, rigidity 40.7%, gait disturbances 34.5%, anxiety 31.3%, pain 28.5%, fatigue 28.3%, depression 27.6%, tremor 20.8%, and appetite disorders 13.2%. In patients with PD, the global subjective negative impact of the COVID-19 pandemic on a scale from 0 (none) to 10 (maximum) was  $6.6 \pm 2.4$  (range, 0–10),

**TABLE 1.** Sociodemographic data of the sample (N = 568)

Sociodemographic variables	N = 568
Age, yr	$63.5 \pm 12.5$ (30–92)
Female	53.0%
Disease duration, yr	$8.4 \pm 5.6$ (1–30)
Race	
Caucasian	97.2%
Black	0.5%
Asian	0.4%
Other	1.9%
Level of education	
Primary	31.2%
Secondary	26.9%
University	41.9%
Marital status	
Married	72.7%
Single	9.5%
Widower	9.2%
Divorced	6.5%
Other	2.1%
Living at home	
With spouse	43.7%
With spouse and son and/or daughter	30.1%
With a son and/or daughter	6.0%
Alone	8.6%
Other	11.6%
Habitat	
Rural (<5000 habitants)	13.5%
Semiurban (5000–20,000 habitants)	14.1%
Urban (>20,000 habitants)	72.4%
Work activity	
No	82.7%
Yes	17.3%
Pension and/or economy support	
Yes	72.7%
No	27.3%
Degree of independence for activities of daily living	
Completely independent	34.2%
Help only for a few things	43.0%
Dependent	21.8%
Unknown	1%
Self-perceived quality of life	
Very good	8.3%
Good	37.1%
Regular	39.8%
Bad	11.4%
Very bad	2.5%
Unknown	0.9%

The results represent percentages or mean  $\pm$  standard deviation.

with 60% of the scores between 7 and 10. There were no differences about the impact of the COVID-19 pandemic regarding age and sex.

With regard to the caregiver ( $n = 326$  for this analysis), 63.5% of the patients had a principal caregiver (mean age,  $60.8 \pm 13.3$  years [21–89]; 75.1% female): 195 a family member (71.9% spouse; 23.7% a son and/or daughter) and 12 a professional caregiver. In caregivers, the global subjective negative impact of the COVID-19 pandemic from 0 to 10 was  $6.9 \pm 2.5$  (range, 0–10), with 64.7% of the scores between 7 and 10.

**TABLE 2.** Symptoms related to PD and other comorbidities (N = 568)

	Patients with COVID-19 (n = 15)	Non-COVID-19 patients (n = 553)	All patients (N = 568)	P (patients with COVID-19 vs non-COVID-19 patients)
Age (yr)	65.6 ± 9.4	63.5 ± 12.6	63.5 ± 12.5	0.520
Females (%)	52.9	53.3	53	0.593
Disease duration (yr)	6.8 ± 4.9	8.5 ± 5.5	8.4 ± 5.6	0.246
PD symptoms (%)				
Predominant hemibody				0.805
Right	40	41.6	41.6	
Left	46.7	37.4	37.7	
Symmetric	13.3	20.6	20.4	
Tremor	73.3	55.1	54.9	0.127
Rigidity				0.676
Yes, continuously	33.4	41.4	41.1	
Yes, but occasionally	53.3	50.7	50.8	
Motor fluctuations	35.7	61	60.4	0.052
Dyskinesia	53.3	55.9	55.9	0.521
Falls				0.193
Yes, often	0	17.8	17.3	
Yes, but rarely	53.3	41.3	41.1	
Bad mood/depression	57.1	65.6	65.4	0.346
Anxiety	60	65.8	65.6	0.414
Pain				0.102
Yes, every day	26.7	50.4	49.7	
Yes, but occasionally	60	33.9	34.6	
Cognitive problems	38.5	36.2	36.2	0.538
Dementia	6.7	16.2	15.9	0.280
Hallucinations	0	23.4	22.8	<b>0.025</b>
Behavioral disorders	15.4	33.6	31.5	0.139
Comorbidities (%)				
Arterial hypertension	26.7	24.3	24.4	0.519
Diabetes mellitus	20	9.7	10	0.181
Dyslipidemia	64.3	24.1	25.1	<b>0.002</b>
Ischemic cardiopathy	13.3	6.9	7	0.285
Valvular cardiopathy	6.7	4.9	4.9	0.534
Cardiac arrhythmia	20	12.7	12.9	0.305
Cardiac insufficiency	6.7	4.2	4.3	0.488
Pulmonary disease	14.3	9.4	9.5	0.391
Any other severe disease				0.311
Oncological disease	0	3.1	3.1	
Rheumatic disease	0	11.7	11.5	
Another disabling disease	0	8.2	8	
Smoking	6.7	8.3	8.3	0.642
Complementary therapies (%)				
PD association	60	56.6	56.3	0.796
Physiotherapy	66.7	58.7	58.9	0.368
Exercise	78.6	64.7	65	0.217
Speech therapy	33.3	47.4	47	0.210
Cognitive stimulation	33.3	57.3	56.7	0.057

The results represent mean ± standard deviation or percentage (%). Chi-square and Mann-Whitney-Wilcoxon test were applied. Positive responses are shown. In the case of unknown, the percentage was low (from 0.4% for smoking to 4.9% for behavioral disorders).

Abbreviations: PD, Parkinson's disease; COVID-19, coronavirus disease 2019. A significance value of  $P < 0.05$  is expressed in bold.

When patients with PD who had COVID-19 were compared with patients who did not have the infection, none of the patients who had COVID-19 had hallucinations compared with 23.4% of those who did not have the infection (Table 2, patients with COVID-19 vs patients without COVID-19;  $P = 0.025$ ). Motor fluctuations (61% vs 35.7%), dementia (16.2% vs 6.7%), and behavioral disorders (33.6% vs 15.4%) were about

double in patients who did not have COVID-19 than in those who had it (a trend toward significance). In general, cardiovascular risk factors and cardiovascular diseases were more frequent in patients who had COVID-19 compared with those who did not have the infection. The difference was significant in the case of dyslipidemia (64.3% vs 24.1%;  $P = 0.002$ ). However, none the patients who had COVID-19 suffered from

oncological and/or rheumatic disease. Interestingly, none of the patients receiving amantadine ( $n = 82$ ) suffered from COVID-19 infection ( $P = 0.064$ ).

## Discussion

This study, the largest one conducted to determine the impact of COVID-19 on patients with PD, found that most patients were aware of the COVID-19 pandemic, were fearful of the risk of contagion, and met prevention standards in a remarkably responsible way. Furthermore, more than half of the patients answered that their PD symptoms had worsened during confinement. Although the study was not designed to determine the prevalence of COVID-19, the data suggest that the percentage of patients affected by the infection could be rather low.

Three studies using a similar methodology, a semistructured interview directed at patients and/or caregivers, have been published to date.<sup>9-11</sup> Prasad et al.<sup>9</sup> reported that 100% of 100 patients and 100 caregivers were aware of the pandemic in a study conducted in India. Of 99 patients with PD from Germany, all but 3 patients (missing data) answered being informed, more than half well or very well, and even 5.1% with too much information about the virus. As in previous studies, the most widely used medium for receiving information was television. However, Spanish patients with PD who participated in this study were more fearful of contracting COVID-19, up to 42%, compared with less than 10%<sup>9</sup> or 28%<sup>11</sup> in other studies. A consequence of this fear could be the high degree of compliance with prevention standards according to the responses obtained, with nearly 90% complying with rigorous containment, hand washing, and use of a mask.

An important observation is that up to 66% of the patients perceived a worsening of their symptoms during confinement, and up to 70% answered that the pandemic had had a negative impact on them. Bradykinesia, sleep problems, rigidity, and gait disturbances were the symptoms that most frequently worsened, probably related to decreased physical activity and psychological stress. Our results are in line with a previous study conducted in Italy,<sup>12</sup> which, like Spain, has been one of the countries most punished by COVID-19. The closure of patient associations and confinement have caused a decrease in patient mobility,<sup>2,7,13</sup> despite the fact that in our population up to 72.7% answered staying active doing exercises and almost half performed therapies after having contacted the Spanish Parkinson's Federation or a patient association website. Moreover, social distancing may result in feelings of loneliness and depression,<sup>13,14</sup> and psychological stress reduces the efficacy of dopaminergic

medications.<sup>15</sup> Very recently, 55% of people with PD reported worsening of an existing motor symptom, and more than 50% reported worsening of nonmotor symptoms regarding the results (unpublished data) of an online survey promoted by the Michael J. Fox Foundation with more than 7200 responses.<sup>16</sup> The consequences of the pandemic on the medical care of patients is another factor to consider.<sup>17-23</sup> Finally, the pandemic has had consequences not only on patients but also on caregivers, as reported previously.<sup>24</sup> Our results showed that the overall mean impact of the pandemic on the PD patient's caregiver was similar to that of the patient.

Only 15 of 568 patients responded that they had COVID-19 (2.6%). This percentage is low and is in line with previous studies: 1.5%,<sup>10</sup> 4.8%,<sup>25</sup> and 7%.<sup>26</sup> Particularly, in the largest online survey conducted to date, of 7209 responses from people with or without PD, only 77 (1.1%) reported a COVID-19 diagnosis.<sup>16</sup> Although the sample size of the group who developed COVID-19 from our study is very small and constitutes an important limitation, three interesting findings could be suggested. First, having an advanced disease with dementia and behavioral disorders could predispose to a lower risk for development of COVID-19, possibly in relation to stricter applied prevention measures. Second, cardiovascular risk factors may increase the risk for COVID-19. The latest evidence indicates that COVID-19 symptoms are most severe in elderly individuals with various comorbidities, such as hypertension, cardiovascular disease, diabetes mellitus, and renal disease.<sup>27-29</sup> Finally, none of the patients receiving amantadine (16.5%) in our study experienced development of COVID-19. It has been suggested that adamantanes might be protective from COVID-19.<sup>30,31</sup>

In conclusion, although this study has limitations because of the methodology, it demonstrates that Spanish patients with PD perceive the COVID-19 pandemic with concern and great responsibility. More than half experienced worsening of their symptoms during confinement. More studies to know the impact of the pandemic globally are needed. ■

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## Supporting Data

Additional Supporting Information may be found in the online version of this article at the publisher's web-site.