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**A French survey on the lockdown consequences of COVID-19 pandemic in Parkinson's disease: a comparison among community-based and hospital-based patients. The ERCOPARK study**

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## **Abstract**

Background: The coronavirus disease 19 (Covid-19) pandemic increased the vulnerability of people with Parkinson's disease (PwP). We investigated the consequences of the first Covid-19 lockdown (mid-March – mid-April 2020) in a cohort of French PwP and analyzed its impact in community-based versus hospital-based PwP.

## Methods

PwP were enrolled either by an on-line survey sent from the national France Parkinson association (FP) to reach the French community of PwP or as part of outpatients' telemedicine visits followed by an hospital-based Parkinson Expert Center (PEC). All patients were evaluated using the same standardized questionnaire assessing motor and non-motor aspects (including a list of most disabling, new or worsened symptoms and Patient's Global Impression-Improvement scales [PGI-I]) psycho-social queries and quality of life.

## Results

2653 PwP were included: 441 (16.6%) in the PEC group and 2122 (83.4%) in the community-based group. Physiotherapy was interrupted among 88.6% of the patients. 40.9% referred a clinical modification of their symptoms. Based on the questionnaire, pain (9.3%), rigidity (9.1%) and tremor (8.5%) were the three most frequently new or worsened reported symptoms. Based on the PGI-I, the motor symptoms were the most affected domain, followed by pain and psychic state. PwP in community-based group tended to have more frequent worsening for motor symptoms, motor complications, pain and confusion than those of the PEC group.

## Conclusions

PwP may be exposed to increased vulnerability to the stressful effect of Covid-19 outbreak. Community-based patients seem to have suffered the most emphasizing the risk of deterioration in care continuity during lockdown.

## **Introduction**

Since the Coronavirus disease 2019 (Covid-19) pandemic started, physicians questioned on whether there could be severe consequences of the Severe Acute Respiratory Syndrome Coronavirus 2 (SARS-CoV-2) infection on Parkinson's disease (PD) symptoms [1] or whether people with Parkinson's disease (PwP) were more vulnerable to SARS-CoV-2 infection [1, 2]. Concomitantly, several studies, although with inconstant results, suggested that pandemic-related lockdown, inducing social and familial isolation, could negatively affect mental and physical well-being, motor, non-motor symptoms (NMS) and quality of life (QoL) of PwP [3-5]. Additionally, the impact of Covid-19 on usual medical care could be not negligible [6].

While it is important to understand and assess the direct and indirect consequences of the COVID 19 pandemic for PwP, it is also relevant to understand the direct and indirect impact of a lockdown on PwP. This is indeed a totally novel situation and the resilience capacities of PwP and conversely their dysexecutive difficulties, could constitute factors of uncertainty.

Our study aimed to investigate the consequences of the Covid-19 pandemic lockdown on a large cohort of French PwP and to analyze the different impact on patients who had a neurological evaluation in academic centers during this period vs. a community-based group of patients.

## **Patients and methods**

Patients were enrolled following two recruitment strategies. First, PwP were included in nine French PD Expert centers (PEC) from the French NS-Park/FCRIN Network (Besancon, Caen, Lille, Marseille, Rouen, Nimes, Reims, Saint-Denis, Toulouse, and Paris) (PEC group). Eligibility criteria were: diagnosis of PD and having a routine follow up scheduled within the first French lockdown duration (16<sup>th</sup> March -- 16<sup>th</sup> May 2020). Exclusion criteria were atypical Parkinsonism and patients already identified as demented according to the DSM-IV criteria. PEC patients' group evaluation was carried out either via telemedicine (by video-consultation or phone call) or during a classic routine follow-up consultation by a movement disorder specialist. Secondly, other PD patients were invited to participate to an online anonymous survey, available online between 20<sup>th</sup> April and 16<sup>th</sup> May 2020, by receiving an email from the France Parkinson Association (FP), i.e. the community-based group. It was specified to the patients to answer only if they had already received a diagnosis of PD, and

were able to answer, and not to fulfill the questionnaire whether they had participated with their neurologist to the survey.

The national medical ethical commission approved the study (protocol number: 2020-Ao1463-36). All participants gave their informed consent prior to completing the questionnaire.

The patients were questioned about their changes occurring after the first month of the 2020 lockdown, i.e. from mid-March up to mid-April. The following data were collected: I) demographic, clinical characteristics and medical care changes, including the interruption of physiotherapy or speech and language therapy sessions. Information about presence of clinical infectious symptoms such as cough, fever or breathing difficulties and Covid diagnostic screening test (positive PCR or thorax scanner) have been also collected; II) changes in motor and NMS evaluated by a patient's Global Impression-Improvement (PGI-I) scales. PGI-I was adopted for 7 domains: general motor PD symptoms (tremor, rigidity and bradykinesia), dyskinesia, motor fluctuations, pain, impulse control disorders (ICDs), psychic state (anxiety and depression) and confusion-hallucinations.; III) Troublesome/worsened symptoms. Patients were asked to spontaneously report at most three new troublesome or worsened symptoms [7]; IV) The psycho-social repercussions of the lockdown evaluated by a numerical scale (varying between 0 [lack of fear] and 100 [maximal fear]) in three situations: a) fear of the contingency of lacking of their anti-parkinsonian treatment (fear); b) exacerbation of their feeling of frailty linked to PD (vulnerability feelings); c) the increased fear of the progression of PD with the pandemic (worrying ideas).; V) QoL assessed by the Parkinson's disease questionnaire (PDQ-8).

Our primary objective was to identify the impact Covid-19-lockdown on motor and NMS of. The related outcomes were the three most "troublesome or worsened" symptoms, the most frequent PGI-I changed and a "several clinical aggravations", i.e. a worsening of at least 5 CGI-Is..

Our secondary objectives were: a) to identify any difference on Covid-19-lockdown impact between the community-based vs. PEC group; b) to assess the psychosocial, by means of VAS scales analysis.

## **Statistical analyses**

To compare characteristics of PEC group vs. community-based group, Chi<sup>2</sup> test was used for qualitative variables (or Fisher's exact test as appropriate) and Wilcoxon rank-sum test for quantitative variables.

To evaluate associated factors to "severe clinical aggravation", logistic regression models were performed. First, univariate models were built with severe clinical aggravation as response variable and one of these data: age, sex, disease duration, center (community-based vs. PEC group), presence/absence of device-aided therapies as explanatory variable (five univariate models). Then, all the explanatory variables were included in a multivariate model. No selection method was used.

All statistical tests were two-sided and p values < 0.05 were considered statistically significant.

All analysis was performed with SAS® statistics software, version 9.4 (SAS Institute Inc., Cary, NC).

## **Results**

### *Demographic and clinical features*

We enrolled 2717 patients but 64 patients from the community-based group were excluded as they declared to have PD for at least 5 years but remained untreated.

2653 PwP were included in the analysis: 441 (16.6%) in the PEC group and 2122 (83.4%) in the community-based group. 2.8% reported infective symptoms and 0.7% had a diagnostic positive test for Covid-19 diagnosis.. Patients belonging to the PEC group had a longer disease duration, were younger and were more frequently treated with a device-aided therapies if compared to the community-based group (respectively 155 [35.1%] vs. 295 [13.3%], p <0.0001) (Table S1, Supplementary material).

### *Consequences on non-pharmacological treatments*

Among the PwP who had physiotherapy (N= 2155), 89.6% were not able to continue their rehabilitation and 98.8% interrupted their speech sessions, out of the 1143 patients previously concerned.



### Motor, non-motor symptoms and quality of life changes

Regarding the self-reported symptoms, 1085 patients (40.9%) indicated that they felt a modification of their PD symptoms during the lockdown (Table 1). Pain, rigidity and tremor were the most troublesome changed symptoms, reported by 9.3%, 9.1%, and 8.5% of the patients, respectively (Figure 1, Panel A and Table 2).

Regarding PGI-I domains (Table 1; Figure 1, Panel B), the motor one was the most frequently affected (55.8%), followed by pain (51.5%) and psychic state (46.3%).

A severe clinical aggravation was observed in 498 patients (18.8%), (Table 1).

Patients with at least five worsened PGI-I ( $44.2 \pm 19.1$ ) had significantly higher mean PDQ 8 scores than less aggravated patients ( $17.6 \pm 16.5$ ) ( $p < 0.0001$  QoL; Figure S2 panel B).

### Psychosocial repercussions

Fragility feelings related to the pandemic was the main concern (mean  $\pm$  SD:  $41 \pm 34.6$ ), followed the concern about the evolution of their disease ( $31.6 \pm 31.4$ ), while patients were less worried about treatment lacking ( $20.9 \pm 20.2$ ) (Figure S1, Panel A).

### PEC versus community-based group

Patients belonging to the community-based group discontinued significantly more frequently physiotherapy if compared to the PEC group (9.8% vs. 6.5%,  $p = 0.01$ ).

Regarding the self-reported symptoms, the percentage of patients without any change was significantly higher in the community-based group than in the PECs (respectively 1453 [65.7%] vs. 115 [26.1%]  $p < 0.0001$ ) (Table 1).

Pain, anxiety, and tremor were on the top of the PEC group list, while rigidity, pain and tremor, on the top for the community-based group, with similar frequency for all the other symptoms (Table 1).

Conversely, patients in the community-based group had significantly more frequently a worsening at all the motor PGI-I scores than in the PEC group: respectively for general motor symptoms (1244 (56.2%) vs. 207 (47%)); dyskinesia (695 (31.4%) vs. 87 (19.7%)) the motor fluctuations (863 (39%) vs. 127 (28.8%)), with in both  $p < 0.0001$  (Table 1). Similarly pain and confusion were significantly more frequently worsened in the community-based group than in

the PEC group (respectively 1169 (52.8%) vs. 167 (37.8%) and 644 (29.1%) vs. 70 (15.8%), in both  $p < 0.0001$ ) (Table 1).

The community-based group had a higher prevalence of “severe clinical aggravation” with 158 patients (20.7%) vs. 40 (9.1%) in the PEC group ( $p < 0.0001$  Table 1).

All VAS scales for psychosocial repercussions showed a higher impact on the community-based group if compared to the PEC group ( $p < 0.0001$ ) (Figure S1, Panel B).

Scores of all PDQ-8 items were significantly worse among the community-based group if compared to the PEC group ( $< 0.0001$ ), except for “dressing” and “personal relationship” (Table 1).

#### Variables related to clinical severe worsening

At univariate analysis, a disease duration longer than 6 years and belonging to community-based group were significantly associated to a “severe clinical worsening” (p values for disease duration: 0.0021 for 7-9 years, 0.0006 for 10-15 years and 0.0083 for  $> 15$  years; p value for center:  $< 0.0001$ ). The same variable kept significance at logistic regression analysis (p values for disease duration: 0.0007 for 7-9 years, 0.0001 for 10-15 years and 0.0058 for  $> 15$  years; p value for group:  $< 0.0001$ ).

## **Discussion**

The present research evaluated the impact of the first COVID-19-related lockdown on PD patients in France, in one of the largest PD cohort ever published. Our sample is representative of a national PD population, being made up of nearly 2% of the French PwP.

We have sought to insight the key role of patients’ perspective by chosen easy tools to assess patients’ changes, (i.e. the spontaneous reported symptoms, the PGI-I and numeric scales) but also to compensate the lack of previous evaluation before the pandemic.

It is noteworthy that more than half of the patients (59.1%) did not referred a change in their symptoms . However, even if considering each single PGI-I domains, a worsening ( $PGI-I \geq 5$ ) was observed in not more than 55% of the patients (range 11.5%-54.6%), only 20.4% of them do not report any worsening at PGI-I assessment (Table 1). Discrepancies among self-reported symptoms vs. PGI-I-assessed ones could be related to the fact that for PGI-I each symptom was specified thus possibly suggesting” the reported worsening, while for the self-reported list no domain/symptom was specified within the question.

A partial stability of PD symptoms was also observed by the few previous studies [3, 8, 9] And multiple factors could also be related to symptoms stability: a) better adherence to treatment [8, 9]; b) better organization of the routine activities, including the possibility to practice physical activity using satisfactorily technology assistance, as reported in 50% of PwP in a previous study (mostly true for women) [10]; c) the resilience capacity of patients, not feeling the restriction to be at home or perceiving a lower disability while staying at home because not facing “outdoor challenging situations”. Identifying patients with a stable profile is interesting, as they seemed to cope better and possibly having better self-management capacities. .

At the same time, we found an impact of the lockdown on motor NMS and QoL in at about half of the patients. Based on the patients ‘perception, general parkinsonian motor symptoms and pain were the most worsened, which was consistent and reinforced with the results of the PGI-I. 45% of the patients had from mild to severe aggravation for psychic state alteration (anxiety and depression) which is unsurprisingly and probably related to the first COVID-19 quarantine and not only to the pandemic. The concomitant aggravation of motor symptoms, such as tremor and rigidity, particularly sensitive to stress may be related to anxiety/depression aggravation, as well as to the diffuse interruption of physiotherapy. Even if a possible confusion between rigidity and pain may explain this result, particularly for the patients who participated to the on-line survey, pain was the most frequent aggravated symptoms also for the PEC group. Non-parkinsonian patients with chronic pain have shown significant aggravation during the same lockdown period [11], suggesting that it could not-being a disease-specific aggravation, quite common in chronic disease at pandemic time. However, considering the high impact of pain on PD QoL, clinicians should be aware that its aggravation could be as much important or even more severe that the one of motor symptoms during stressful situations.

The community-based group’s patients seemed to worsen less in agreement with the three spontaneous symptoms, though a more severe aggravation was observed at the PGI-I. Although it might seem discordant we thought that there could have been a bias induced by the neurologist when asking the patients for his spontaneous symptoms. Additionally, the more severe deterioration of the community-based group, confirmed at the regression analysis, is equally reflected by worst QoL scores and higher psycho-social repercussion (Figure S1, Panel B).

A more severe aggravation of the community-based group could be accounted to an easier access to clinics for the PEC group. However, we cannot completely exclude that some community-based patients also had a neurological visit but likely not in an PEC. Limited access to health care resources associated with restrictions of mobility and social interactions may have played a more negative role in the community-based group [12]. Changes are ongoing worldwide to implement telemedicine for urgent or even for current routine healthcare [3] as whether videoconferencing or simple phone consultations could preserve the more fragile PD patients. Identifying them and their needs to keep a continuous healthcare management is a condition needed to protect them from an expected worsening in such a crisis.

There are limitations mainly related to the online patient-based survey and the lack of a clinically in-person assessment that cannot guaranty us that no patients with severe cognitive decline answered the survey. Additionally, only very few institutionalized patients were included, and the survey excluded demented patients, thus giving a not a complete representation of the whole PD population.

In conclusion, our large cohort study highlights that the COVID-19-related lockdown has exacerbated motor and NMS in about half of the included PD patients, with a more severe aggravation among the community-based group.

Developing alternative strategy to maintain the access to standard neurological cares such as telemedicine could have been useful, as continuity in care seems to positively affect patients' outcomes.

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The authors declare that there are no conflicts of interest relevant to this work.

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## LEGEND FOR TABLES

**Table 1.** Symptoms' evolution and PGI-I worsening comparison between the Community-based group and the PEC group. Numbers are represented as mean (SD). PGI-I varied from 1 (best improvement) to 7 (worse aggravation), being a score  $\geq 5$ , the cut-off for an aggravation).

## LEGEND FOR FIGURES

### Figure 1. Symptom's evolution.

Panel A: Distribution of the new or worsened troublesome symptoms named by the patients.

Panel B: results of the motor and non-motor PGI-I in the whole population.

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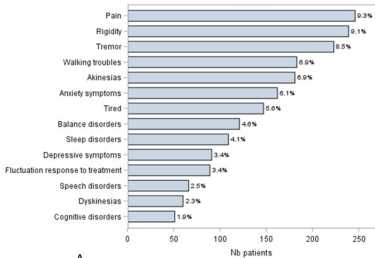
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### Evolution of symptoms

>= 2% of patients

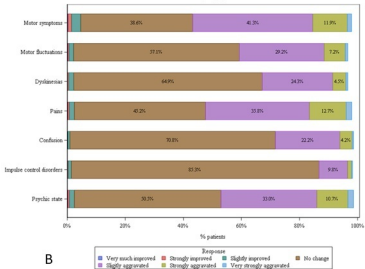
N = 2653



A

### PGL1

N = 2653



B

**Table 1.** Symptoms' evolution and PGI-I worsening comparison between the Community-based group and the PEC group.

	<b>Total</b> N= 2653	<b>PEC group</b> N= 441	<b>Community-based group</b> N= 2212	<b>Community-based group vs. PEC group</b>
	N patients (%)	N patients (%)	N patients (%)	p value
<b>Number of worsened symptoms</b>				
<b>1</b>	293 (11.4)	63 (14.29)	230 (10.4)	<0.0001
<b>2</b>	292 (11.01)	105 (23.81)	187 (8.45)	<0.0001
<b>3</b>	498 (18.77)	158 (35.83)	340 (15.37)	<0.0001
<b>No worsening</b>	1568 (59.1)	115 (26.8)	1453 (65.6)	<0.0001
<b>Worsened symptoms, as listed by the patients</b>				
Pain	246 (9.2)	84 (19.5)	162 (7.3)	<0.0001
Rigidity	239 (9.0)	48 (10.8)	191 (8.6)	0.13
Tremor	223 (8.4)	66 (14.9)	157 (7.1)	<0.0001
Walking troubles	183 (6.9)	48 (10.8)	135 (6.1)	0.0003
Akinesia	181 (6.8)	46 (10.4)	135 (6.1)	0,001
Anxiety	162 (6.1)	73 (16.5)	89 (4.0)	<0.0001
Fatigue	147 (5.4)	39 (8.4)	108 (4.8)	0,0009
Balance disturbances	121 (4.5)	20 (4.5)	101 (4.5)	0.98
Sleep disorders	109 (4.1)	42 (9.5)	67 (3.0)	<0.0001
<b>PGI-I</b>				
<b>PGI-I<math>\geq</math>5_motor symptoms</b>	1451 (55.8)	207 (46.9)	1244 (57.6)	<0.0001
<b>PGI-I<math>\geq</math>5_dyskinesia</b>	782 (30.5)	87 (19.7)	695 (32.7)	<0.0001
<b>PGI-I<math>\geq</math>5_motor fluctuations</b>	990 (38.6)	127 (28.8)	863 (40.7)	<0.0001
<b>PGI-I<math>\geq</math>5_Pain</b>	1336 (51.4)	167 (37.9)	1169 (54.1)	<0.0001
<b>PGI-I<math>\geq</math>5_confusion</b>	714 (27.3)	70 (15.9)	644 (29.6)	<0.0001
<b>PGI-I<math>\geq</math>5_ICD</b>	305 (12)	53 (12.0)	252 (11.6)	0.82
<b>PGI-I<math>\geq</math>5_psychic state</b>	1211 (46.3)	210 (47.6)	1001 (46.0)	0.53
<b>Number of worsened PGI-I per patient</b>				
Missing data				
	4 (0.15)	/	4 (0.15)	1
<b>0</b>	540 (20.4)	99 (22.5)	441 (19.9)	<0.0001
<b>1</b>	367 (13.8)	85 (19.3)	282 (12.8)	
<b>2</b>	416 (15.7)	83 (18.8)	333 (15.1)	
<b>3</b>	435 (16.4)	76 (17.2)	359 (16.2)	
<b>4</b>	393 (14.8)	58 (13.2)	335 (15.1)	
<b>5</b>	309 (11.65)	30 (6.8)	279 (12.6)	
<b>6</b>	155 (5.9)	10 (2.3)	145 (6.6)	
<b>7</b>	34 (1.3)	0 (0)	34 (1.5)	
<b>At least 5 PGI-I <math>\geq</math>5</b>				
<b>5 PGI-I <math>\geq</math>5</b>	493 (18.8)	40 (9.1)	458 (20.7)	< 0.0001
<b>PDQ-8</b>				
<b>Total score, mean (SD)</b>	29.4 (19.7)	25.6 (17.2)	30.1 (20.0)	<0.0001
Difficulty getting around in public	25.4 (31.9)	24.1 (34.1)	25.6 (31.5)	0.04
Dressing	30.4 (31.8)	32.7 (33.7)	29.9 (31.4)	0.21
Depression	34.3 (27.3)	26.9 (28.0)	35.7 (26.9)	<0.0001
Personal relationship	37.0 (28.5)	35.7 (32.5)	37.2 (27.7)	0.16
Concentration	33.6 (28.6)	28.2 (31.1)	34.0 (28.2)	<0.0001
Painful cramps	29.9 (29.5)	24.1 (31.2)	31.1 (29.0)	<0.0001
Embarrassed in public	19.2 (24.9)	12.0 (24.2)	20.6 (24.8)	<0.0001

Number are represented as mean (SD). PGI-I varied from 1 (best improvement) to 7 (worse aggravation), being a score  $\geq$ 5, the cut-off for an aggravation). PGI-I: patient's Global Impression-Improvement; PDQ-8: Parkinson's disease questionnaire.