

Covid-19 perception and self reported impact of pandemic on Parkinson's disease symptoms of patients with physically independent Parkinson's disease

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Abstract

Objective: The novel coronavirus disease 2019 (Covid-19) pandemic has affected many people with chronic diseases, including Parkinson's disease (PD). We aimed to investigate the perception of Covid-19 and the self-reported impact of the pandemic on PD symptoms of a group of patients with physically independent PD from Turkey. **Methods:** We applied a questionnaire to idiopathic PD patients aged ≥ 65 years, who did not have known dementia, who were physically independent and who had at least one visit in the year before the telephone interview. The study patients were selected from the medical records of two different centers in Kirikkale, Turkey. Two neurologists conducted a semi-structured telephone interview to evaluate the perception of Covid-19 and new or worsening PD symptoms after the home quarantine. **Results:** In total, 86 patients were included in the study. Although most of the patients (97.7%) knew of Covid-19, knowledge of the Covid-19 symptoms was moderate (54.7%). Most patients reported that they washed their hands often (100%) and wore a mask (98.8%); 76 (88.4%) of them stayed at home. Compliance with other preventive measures was above 80%. In total, 40 (46.5%) patients (28 male, 12 female) reported worsening bradykinesia. Fatigue (24.4%), daytime sleepiness (20.9%), pain (20.9%) and anxiety (15.2%) were the most common new or worsening non-motor symptoms.

Conclusions: The Covid-19 knowledge in a group of patients with PD from Turkey can be considered adequate. They have a high compliance with preventive measures. However, reduced non-exercise physical activity due to the pandemic affected both their motor symptoms and non-motor symptoms.

Keywords: Parkinson's disease, coronavirus, Covid-19, motor symptoms, nonmotor symptoms, movement disorders

INTRODUCTION

A pandemic is the spread of an infectious disease that affects people on a worldwide scale. It may cause excessive deaths and disrupt the healthcare systems and social and economic circumstances of the countries.¹ The novel coronavirus disease 2019 (Covid-19) pandemic began in 2019 and spread rapidly. Covid-19 is caused by severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2). The clinical range of Covid-19 varies from asymptomatic to acute respiratory distress syndrome (ARDS).² An individual infected with SARS-CoV-2 may develop a serious progressive disease, particularly if there is a presence of comorbid conditions and increased age. It is

thought that changes to the immune response and respiratory ciliary activity in the elderly may contribute to the progression of the disease; therefore, measures to prevent Covid-19 infection are crucial.^{3,4}

Neurodegenerative diseases, such as Parkinson's disease (PD), are more common with advanced age.⁵ Although PD typically develops between the ages of 55 and 65 years, there is increased risk at age of over 60 years, rising especially at ages 85–89 years. It is characterised by motor (bradykinesia, tremor, rigidity, postural instability) and various non-motor symptoms (NMSs), such as constipation, urinary disorders, sleep problems, pain, fatigue, and apathy.⁶

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While there is no evidence that patients with PD are at an increased risk of contracting Covid-19, age and PD as a chronic neurologic disease may result in serious complications. Thus, the PD patients should adopt a more strict preventive measures to avoid contacting the disease. Staying at home (home quarantine) as a preventive measure has been adopted for almost three months (between 21 March 2020 and 9 July 2020), particularly by persons aged ≥ 65 years in Turkey.⁷ However, the stress related to a possible infection and reductions in non-exercise physical activity may worsen PD symptoms.⁸ In this study, we aimed to investigate the perception of Covid-19 and the impact of the pandemic on self-reported symptoms among a group of PD patients in Turkey.

METHODS

This semi-structured survey study was conducted by telephone interview after 3-months home quarantine. A university ethics committee approved the study.

The patients were enrolled from two different centres (University and local hospital) in the Kirikkale city, Turkey. PD patients aged ≥ 65 years who were not known to have dementia and who had at least one visit in the past year were selected from the medical records. Patients who were physically independent (Hoehn and Yahr staging, HYS ≤ 3) were included to determine the impact of reduced non-exercise physical activity on motor symptoms and NMSs. The diagnosis of PD was according to the United Kingdom Brain Bank criteria.⁹ Exclusion criteria were hydrocephalus, brain tumours, repetitive head trauma, prolonged use of neuroleptics that may be the cause of secondary parkinsonism, abrupt onset or gradual progression of disease symptoms, unresponsiveness to levodopa, stroke, orthopaedic problems that prevent walking and severe hearing loss. Age, gender, education level (according to the local education system), modified-HYS, current daily levodopa equivalent dose (LED) and disease duration were recorded from one to nine months before home quarantine.

Questionnaire

The questionnaire consisted of 14 questions. The first 11 were to assess the patient's Covid-19 knowledge (Questions 1, 2), compliance with preventive measures (Questions 3–9), risk perception (Question 10) and history of Covid-19 (Question 11). A minimum of two symptoms

(dyspnea, cough, fever) of Covid-19 were accepted as yes for Question 11. A PD-specific section of the questionnaire asked about the impact of the pandemic on medical adherence (Questions 12, 13) and new or worsening symptoms of PD (Question 14) in the last three months before the interviews. Each question was answered with a yes or no (Table 1). If Question 14 was answered with a yes, each motor symptom (tremor, bradykinesia and postural instability) and NMS (cognitive impairment, hallucination and psychosis, depressed mood, anxious mood, apathy, features of dopamine dysregulation syndrome, sleep problems, daytime sleepiness, pain, urinary problems, constipation problems, orthostatic hypotension as light-headedness upon standing and fatigue) were assessed. Bradykinesia with slowness of movement in daily living activities (dressing, eating tasks, hygiene, hobbies) and postural instability (inability to balance during the quick movements) was questioned. NMSs were explained to the patients according to the Movement Disorder Society-Unified Parkinson's Disease Rating Scale (MDS-UPDRS) Part I.^{10,11} Five patients completed the questionnaires before the study, and the questions were found to be well understood by the patients.

Before the interview, a neurologist informed the patient of the aim of study and the estimated duration of the survey.

Data analysis

Continuous quantitative variables were expressed in terms of mean and standard deviation values. Qualitative variables were expressed in terms of minimum and maximum values. To test the quantitative variables, the independent *t*-test was used for normally distributed data. The Mann–Whitney U test was used for non-normally distributed data. The Spearman's correlation test was used for data that was not normally distributed. P values of < 0.05 were considered statistically significant. All data analyses were performed using the SPSS 21 package programme (SPSS Inc., Chicago, Ill, USA).

RESULTS

In total, 144 patients were screened and found to be suitable for the study; out of whom 51 could not be reached by telephone because a telephone number was not included in the medical records. Five patients died due to cardiovascular disease, and two suffered severe hearing loss. Altogether, 86 patients were included in the study.

Table 1: Questionnaire on perception of COVID-19

| Data (%) | Total (n:86) | |
|--|--------------|------|
| | Yes | No |
| Knowledge | | |
| 1. Do you know about coronavirus disease? | 97.7 | 2.3 |
| 2. Do you know about the complaints of coronavirus disease? | 54.7 | 45.3 |
| Compliance of preventive measures | | |
| 3. Do you wash your hands often? | 100 | 0 |
| 4. Do you use a disinfectant for your hands? | 93 | 7 |
| 5. Do you wear a mask? | 98.8 | 1.2 |
| 6. Do you avoid touching your face? | 84.9 | 15.1 |
| 7. Do you follow rules of social distancing? | 89.5 | 10.5 |
| 8. Do you stay at home? | 88.4 | 11.6 |
| 9. Do you clean your house often? | 89.5 | 10.5 |
| Risk perception and diagnosis of coronavirus disease | | |
| 9. Do you feel that you are at a higher risk of contracting coronavirus disease? | 88.4 | 11.6 |
| 9. (a) If “yes,” then why? | | |
| Elderly | 58.1 | - |
| Other comorbid disease | 10.5 | - |
| Parkinson’s disease | 10.5 | - |
| Unknown | 11.6 | - |
| 10. Have you or a first-degree relative been diagnosed with coronavirus disease? | 0 | 100 |
| Impact of the pandemic on Parkinson’s disease | | |
| 11. Were you able to maintain your supply of antiparkinsonian medication? | 91.9 | 9.1 |
| 12. Have you stopped taking your antiparkinsonian medication? | 10.5 | 89.5 |
| 13. Have you noticed any new or worsening symptoms during the last three months? | 55.8 | 44.1 |

The demographic and clinical characteristics of the patients who participated in the study are presented in Table 2. Education level was the only demographic variable with a significant difference between the male and female participants ($p=0.25$).

Knowledge of Covid-19, compliance with preventive measures, risk perception and diagnosis of Covid-19 in patients

Although most of the patients (97.7%) knew of Covid-19, the knowledge of Covid-19 symptoms was moderate (54.7%). The perception of risk was found to be 88.4%, with 68 patients aware of their high risk. Almost all of the patients reported that they washed their hands often and wore a mask

(100%, 98.8%, respectively). While 76 (88.4%) of the patients stayed completely at home, 10 (11.6%) stayed at home and visited their relatives. Compliance with other preventive measures was above 80%. None of the patients were diagnosed with Covid-19. The data concerning the knowledge of Covid-19, compliance with preventive measures, risk perception and diagnosis of Covid-19 in patients is shown in Table 2. The percentage of patients who stayed at home and who were aware of their risk was found to be 88.4%.

Impact of pandemic on PD symptoms

Forty (46.5%) patients (28 male, 12 female) reported worsening bradykinesia. There was

Table 2: The demographic and clinical characteristics of patients

| Data | Total patients (n:86) | Female (n:29) | Male (n:57) | p value |
|------------------------------|-----------------------|---------------|--------------|---------|
| Age, years, mean (\pm SD) | 71.15 (5.81) | 71.51 (5.24) | 70.96 (5.12) | 0.68 |
| Gender, | | | | |
| Female / Male | 29 /57 | - | - | |
| Education level, n (%) | | | | 0.25* |
| Illiterate | 21 (24.4) | 12 (57) | 9 (42.9) | |
| Primary education | 43 (50) | 14 (32.5) | 29 (67.4) | |
| Secondary education | 17 (19.8) | 14 (81.2) | 3 (18.8) | |
| High school education | 5 (5.8) | 5 (100) | 0 | |
| Disease duration, years | 4 (0.25-20) | 5.2 (0.5-20) | 4.4 (0.4-20) | 0.50 |
| HYS, median (min-max) | 1.7 (1-3) | 1.6 (1-3) | 1.7 (1-3) | 0.54 |
| LEDD, mean (\pm SD) | 529 (337) | 508 (311) | 540 (352) | 0.67 |

HYS, Hoehn and Yahr staging; LEDD, Levodopa Equivalent dose

* $p < 0.05$

a significant correlation between worsening bradykinesia and LED and HYS ($r_s = 0.489$, $p=0.001$; $r_s = 0.466$, $p=0.002$, respectively). Similarly, a significant correlation was observed between postural instability and LED and HYS ($r_s = 0.653$, $p=0.002$; $r_s = 0.508$, $p=0.026$, respectively). A correlation of bradykinesia with depression and anxiety was not observed ($r_s = 0.011$ $p=0.921$, $r_s = 0.257$ $p=0.551$, respectively). Fatigue (24.4%), daytime sleepiness (20.9%) and pain (20.9%) were the most common new or worsening NMSs.

Most of the patients were supplied with their medications from a pharmacy, but 7 of them stopped taking it. Self-reported motor symptoms and NMSs are shown in Table 3.

DISCUSSION

The Covid-19 pandemic has affected the physical and mental health of individuals with existing diseases in different ways. PD, which has an increased incidence in advanced age, is of greater risk of developing a more serious disease if they develop Covid-19 infection. We observed that the PD patients in our study complied with the preventive measures. We also found that our PD patients have self-reported worsening of mostly bradykinesia and some NMSs. The most common worsening NMSs were daytime sleepiness, pain and fatigue.

The respiratory system may be affected by the underlying pathology or therapy for PD.

Pneumonia may be common as a consequence of respiratory dysfunction, and it may remain a significant cause of morbidity and mortality.^{12,13} Although there are no prior reports of respiratory dysfunction resulting in increased morbidity when PD patients develop Covid-19 infection, this is possible. Consequently, knowledge of Covid-19 and protective measures is particularly important for PD patients. The patients with PD included in our study were aware of Covid-19. Despite low education levels, they reported a high level of adherence to preventive measures, particularly hand washing and mask wearing. They knew that they were at a high risk, with the most common reported reason being an older age. Most patients were unaware of any other interaction between PD and the risk of Covid-19. None of the patients were infected with Covid-19. Knowledge of Covid-19 and preventive behaviours among PD patients from South India and Germany was reported as high during the pandemic.^{14,15} Until now, only a limited number of PD patients were reported to have been infected with Covid-19.^{16,17}

Among those who were included in our study, all of the patients with PD stayed at home, with decreased mobility. Although we observed a high adherence to the PD therapy, half of the patients reported at least one new or worsening symptom. Only five patients stopped taking levodopa, one stopped rasagiline and one stopped a dopamine agonist (due to daytime sleepiness). They complained of worsening bradykinesia as a

Table 3: Self-reported new or worsening symptoms in patients with PD

| Data, n (%) | Yes | No |
|--------------------------------|------------|-----------|
| Motor symptoms | | |
| Bradykinesia | 40 (46.5) | 46 (53.5) |
| Tremor | 18 (20.9) | 68 (79.1) |
| Postural instabilite | 19 (22.1) | 67 (77.9) |
| Nonmotor symptoms | | |
| Pain | 18 (20.9) | 68 (79.1) |
| Constipation | 9 (10.5) | 77 (89.5) |
| Urinary disorder | 5 (5.8) | 81 (94.2) |
| Daytime sleepiness | 18 (20.9) | 68 (79.1) |
| Fatigue | 21 (24.4) | 65 (75.6) |
| Sleep disorder | 4 (4.7) | 82 (95.3) |
| Cognitive impairment | 12 (14) | 74 (86) |
| Hallucination | 5 (5.8) | 81 (94.2) |
| Depression | 2 (2.3) | 84 (97.7) |
| Anxiety | 13 (15.1) | 73 (84.9) |
| Dopamin dysregulation syndrome | 1 (1.2) | 85 (98.8) |
| Apathy | 7 (8.1) | 79 (91.9) |
| Orthostatic hypotension | 26 (30.2) | 60 (69.8) |

motor symptom, and bradykinesia was associated with levodopa and disease stage. Worsening bradykinesia may be a result of the cancelation of their regular medical visits. In the study by Ziipich *et al.*, 31% of the patients reported a decrease in mobility due to worsening PD, which is in line with our study.¹⁵ In contrast, Prasad *et al.* reported that 10–11% patients had worsening PD symptoms, mostly tremors, during the pandemic; however, the patients in their study were younger than the ones in ours.¹⁴ To assess the impact of reduced mobility on PD, we only included physically independent patients in our study, and this is different from the previous studies. The decrease of non-exercise physical activity may be associated with severe motor symptoms and result in an increase in UPDRS-bradykinesia and axial scores in PD.¹⁸ Home exercise may be additionally beneficial for patients in cases of inactivity caused by a sedentary lifestyle or by situations such as a pandemic. Aerobic exercises can improve the motor symptoms of the patients.¹⁹

In our study, we were able to contact elderly patients with PD who did not have electronic devices or e-mail addresses. However, the patients may still have access to the local tele-health

systems. Tele-health systems may be useful to the management of chronic neurological diseases and to patient in developing countries, which have an insufficient neurology human resources.^{20,21} In addition, web-based solutions, which include communication and information, may reduce social isolation and its effects, such as depression, for elderly patients.²² The depression rate was low in the present study. Perhaps this is due to the early stages of social isolation. Furthermore, we did not find any correlation of bradykinesia with depression and anxiety in our study.

We explained the NMSs to patients according to MDS-UPDRS Part I. We could not score NMSs because we could only conduct telephone interviews. A correlation between the MDS-UPDRS Part I and other scales used to assess the NMSs in PD has been reported, including the Scales for Outcomes in Parkinson's Disease–Autonomic (SCOPA-AUT), the Mayo Sleep Questionnaire (MSQ), the Epworth Sleepiness Scale (ESS) and the Neuropsychiatric Inventory Questionnaire (NPI-Q).²³ Our patients reported fatigue as the most common NMS. It is noteworthy that patients from India also reported fatigue as an NMS during the pandemic.¹⁴ Symptoms of fatigue

could be confused with those of depression; however, the patients in the present study seldom reported depression.²⁴ The other NMSs reported most commonly were pain, daytime sleepiness and anxiety. Daytime sleepiness can also be associated with fatigue.²¹ The most common anticipated NMSs due to reduced physical activity during the pandemic period were constipation, insomnia and anxiety.^{9,26} Because of the fear of contracting Covid-19, anxiety was recently reported as higher among the PD patients as compared to the controls.²⁷

This study has some limitations. The presence of falls in patients were not questioned. Various types of exercise and physical activity influence PD motor and non-motor features. Physical activity has been found to have a positive effect on balance, gait and posture, fall or fear of fall.²⁸ Additionally, PD symptoms reported here could not be measured objectively, since they were self-reported and patients do not want to visit a hospital after quarantine because of the risk of contracting Covid-19 infection. We did not evaluate rigidity although it is one of the cardinal symptoms of PD, and it is typically evaluated with a clinical scale (UPDRS-Part II) by a clinician. In addition, there was no local survey to evaluate Covid-19, including knowledge of the disease and compliance with preventive measures.

In conclusion, we observed from a group of physically independent PD patients from Turkey knew about Covid-19 and its risk. They were also compliant with the preventive measures. There was increase in the motor and NMSs, probably from the decrease in non-exercise physical activity because of pandemic regulations.

DISCLOSURE

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