




A telephonic survey of health-related quality of life of outpatient department dropout Parkinson's disease patients during the COVID-19 pandemic

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Received: 7 November 2021 / Accepted: 2 February 2022 / Published online: 17 February 2022
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Abstract

Introduction COVID-19 pandemic has severely jeopardized world health care. The most affected population is of elderly and patients with chronic diseases. The current study aims to investigate the health-related quality of life of Parkinson's disease outpatient dropout patients.

Methods In this cross-sectional telephonic observational study, we investigated the demographic features and quality of life of Idiopathic PD patients (cases) attending neurology clinics during the pre-COVID-19 pandemic for at least 6 months and dropped out after that. We then compared them with their matched controls, who started visiting clinics once the OPD began functioning again. We used the European quality of life (EQ-5Q-5D) scale to assess health-related quality of life (HRQOL).

Results We recruited 31 PD patients and their 42 matched controls. 90.3% of cases reported worsening PD symptoms, and 83.8% were unable to visit a doctor despite the need. The slowness of activities, increase in tremors, and sleep disturbances were the common complaints. 26% of the patients had difficulty procuring the medicines. EQ-5D-5L and Visual analog scale scores were significantly lower in cases versus controls with between mean group difference of -0.2837 ($p < 0.001$, 95% CI -0.4269 to -0.1377) and -21.985 ($p < 0.001$, 95% CI -31.8 to -12.1), respectively, depicting the poor quality of life of cases.

Conclusion There is a significant worsening of disease status and HRQOL of PD patients not attending OPD, which needs urgent interventions. There is an unmet need to actively track these patients and address their issues to provide holistic health care.

Keywords Parkinson's disease · Movement disorders · Quality of life · Telephonic survey · COVID-19

Introduction

The coronavirus disease 2019 (COVID-19) caused by severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) created a worldwide pandemic [1]. On March 11, 2020, WHO declared SARS-CoV-2 a pandemic after the world failed to contain it and speeded it to 114 countries [2]. Numerous strategies have been developed and implemented to halt the progression, including social distancing, mask-wearing in public areas, lockdown of entire countries,

shutting of airports, travel ban, use of various drugs, and vaccine. During this time, healthcare infrastructure was overburdened and had a scarcity of facilities to cater to the population's needs. Many of the hospitals shut down outpatient departments (OPD) and were converted to COVID care hospitals. Patients with Parkinson's disease (PD) are usually frailer than the general population because of their age, disease-related factors and comorbidities. They need regular supervision of their health and, thus, were the worst sufferers of the COVID-19 pandemic.

Moreover, a higher COVID-19-related mortality has been seen among patients with PD [3–5]. As the world started healing with the help of various interventions and ongoing vaccination programs, most hospitals have opened the OPD again. However, many patients with chronic diseases have still not started attending the OPD despite their needs. Our primary aim of this telephonic survey was to

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investigate the impact of COVID-19 on PD patients not attending the OPD and their health-related quality of life.

Materials and methods

In this cross-sectional observational study, we investigated the demographic features and quality of life of patients with idiopathic PD compared to their matched controls. Cases were selected with diagnoses of idiopathic PD as per UK Brain bank's criteria who were regularly attending neurology clinics during a pre-COVID-19 pandemic for at least six months and dropped out after that. Controls were the PD patients who started visiting neurology clinics once the OPD began to function again and only included after 3 months of regular visits. Patients with atypical PD, any major illness during COVID-19 pandemic including COVID-19 positivity, which could have impact the quality of life, and patients unable to communicate on phone were excluded. PD controls were matched for age, disease duration, sex and Hoehn and Yahr staging (H–Y staging) of the disease. The study was done in South India and started after obtaining Institute ethics committee approval. Patients satisfying the eligibility criteria were enrolled in the study. Since this study is telephonic, patients were provided information about the research, and explicit consent was taken. PD patients demographics were recorded, and we asked open-ended questions related to their disease status and impact of COVID-19.

The EuroQoL (EQ-5D-5L) was used as the primary tool to assess the health-related quality of life in PD patients. It is based on five mobility questionnaires, personal care, usual activities, pain/discomfort, and anxiety/depression, each with five options. A higher score indicates more severity or frequency of symptoms. A five-digit number subsequently shows the overall health state. An index score is calculated from the five dimensions from a score table with a maximum score of one indicating best health. EQ-5D-5L also includes a visual analog scale ranging from 0 (death) to 100 (perfect health), depicting the health perceived by the subject.

Statistical analyses

Demographics were described using mean, standard deviation (SD), frequency, and percentage. Unpaired t-test was used for between-group comparison for continuous variables, and Chi-square test was used for categorical variables. A p value < 0.05 was considered significant. Statistical analysis was performed using SPSS software version 28.0 (SPSS Inc., Chicago, IL, USA).

Results

We contacted 48 PD patients telephonically, and 31 patients responded and were included in the study. Among controls, we recruited 46 patients, and 42 patients agreed to participate. The mean age of the patients was 58.26 ± 13.6 years, disease duration 6.06 ± 2.5 years, and H–Y stage was 2.23 ± 1.1 . Baseline characteristics, demographics and clinical features were compared between cases and matched controls (Table 1).

After collecting demographic data, cases were asked open-ended questions regarding their health. Ninety-seven percent of them felt that their health was affected because of the COVID-19 pandemic. Among them, 90.3% responded to worsening their symptoms, and 83.8% could not visit a doctor despite their need. We found that one-fourth of the cases had difficulty in procuring their medications. Worsening of tremors, sleep disturbances, and increased slowness of activities were the main problems. The barriers to hospital visits were no information of doctor availability and difficulty with mobilization. Four cases responded that they stopped taking PD medications (Table 2).

Among the domains of the EQ-5D-5L scale, mobility, usual activities, and anxiety/depression showed significant worsening compared to controls (Table 4). More than 50% of the cases had a moderate difficulty level in the mobility domain and higher than controls with 35%. In the usual activities domain, 9.8% of the patients were unable to perform any activity. Around 20% of cases in the anxiety/depression domain had moderate to severe problems

Table 1 Demographic and clinical variables of cases and controls

	Cases ($N=31$)*	Control ($N=42$)	P value
Age	58.26 (13.6)	61.7(8.7)	0.096
Male gender, N (%)	20 (64.5)	24 (57)	0.275
Disease duration	6.06 (2.5)	6.48 (3.9)	0.307
Hoehn and Yahr stage	2.23 (1.1)	2.24(0.98)	0.480
Hypertension	35%	38%	0.468
Diabetes mellitus	14%	16%	0.151
Heart disease	8%	7%	0.142
Dyslipidemia	11%	8%	0.098
Medications			
Levodopa	27 (87%)	42 (100%)	0.304
Dopamine agonists	6 (19%)	11 (26%)	0.312
Anticholinergic	14 (45%)	27 (64%)	0.094
MAO-B inhibitors	–	1 (2.3%)	–
COMT—inhibitors	–	–	–
Levodopa mean	468.6 ± 246.4	574 ± 268.8	0.078
Equivalent dosage			

* Data are provided as mean (SD) or percentage

Table 2 Implications of COVID-19 in PD patients not attending OPD

Open ended questions	Cases (N=31)
Are you facing any problems because of COVID-19 pandemic?	Yes—30 (97%) No—1
If yes, what is/are the problems?	Worsening of symptoms—28 (90.3%) Unable to visit the doctor—26 (83.8%) Unable to procure the free medications—8 (25.8%)
What are the symptoms that worsened?	Tremors—16 (51.6%) Slowness—11 (35.4%) Stiffness—08 (25.8%) Fall—02 (6.4%) Reduced sleep—14 (45.1%) Fatigability—18 (58.3%) Pain/discomfort—08 (25.8%) Anxiety/depression—11 (30.4%)
What is the main barrier for not visiting the doctor (N=26)?	No information of doctor availability—12 (38.7%) Difficulty in mobility—8 (25.8%) Lack of family support—4 (12.9%) Financial constraints for transport—2 (6.4%)
Are you taking PD medications?	Yes—27 (87.9%) No—4
Has there any change in dosage/medication since the start of COVID-19 pandemic?	Yes—5 (16.1%) No—26

compared to 4.8% in controls. Among the five domains of EQ-5D-5L, anxiety/depression was the least involved affected domain for both cases and controls (Table 3).

An independent sample *t* test was used to determine significant group differences between cases and their matched controls. EQ-5D-5L score was significantly lower in cases than in the control group with a mean group difference of -0.2837 ($p < 0.001$, 95% CI -0.4269 to -0.1377). Visual analog scale also showed significant mean group difference of -21.985 ($p < 0.001$, 95% CI -31.8 to -12.1) compared to controls ($p < 0.001$, 95% CI -31.8 to -12.1) (Table 4).

Discussion

To our knowledge, this is the first study involving the telephonic survey of PD patients who did not attend the OPD following the COVID-19 pandemic and comparing with those who attended it. Most of the patients OPD dropout patients felt that their health was affected due to the pandemic. They reported an increase in tremors, stiffness, and slowness of activities, fatigability and sleep problems. In a study done in the Netherlands, 46% of the PD patients reported worsening tremors, rigidity, fatigue pain, and concentration during the pandemic [6]. In an online survey done in the USA, 52% and 45% of PD patients reported worsening non-motor symptoms and motor symptoms, respectively [7]. In our study, about 25% of the patients had difficulty procuring the medicines. This led to frequent missing of drug dosages and significantly impacted their life. We found

that four patients altogether stopped taking drugs because of difficulty in procuring. This resulted in significant slowing and difficulty in performing usual activities. In a global survey of PD patients, 45% reported worsening in the Heath status during the COVID-19 pandemic, and 22.8% stated difficulty in procuring medicines [8]. In the EQ-5D-5L questionnaire, patients reported the most difficulty in mobility and performing usual activities. Around 26% of the patients said that they had trouble visiting OPD because of mobility problems. In a scoping review of 31 studies on the impact of COVID-19 on PD patients, discontinuation of regular healthcare appointments, lack of physical activity, and loss of social support led to significant worsening of symptoms and poorer mental health [9].

Another important finding in our study was that many patients were not aware of the reopening of healthcare facilities. This stresses the need to actively track and inform the patients regarding the availability of healthcare facilities. This can be only achieved through the active participation of healthcare providers, various government and private organizations. Different sources such as print media, text messages and electronic media can be used to inform the patients.

Our study found that the health-related quality of life of PD patients who did not attend OPD is significantly worse than their matched PD controls attending OPD. More than half of the patients had difficulty in mobility and usual daily care activities. In addition, they had significant pain/discomfort, difficulty in self-care and suffering from anxiety and depression. Most OPD dropout patients continue to take the same medicines of pre-COVID times despite a significant

Table 3 Self-reported health by PD patients using EQ-5D-5L descriptive scale using independent sample *t* test

Domain		Cases (<i>N</i> —31) <i>N</i> -%	Contro l(<i>N</i> —42) <i>N</i> -%
Mobility	No problems	29	45.3
	Slight problems	16.1	19
	Moderate problems	25.8	14.3
	Severe problems	22.6	21.4
	Unable to	6.5	0
Self-care	No problems	38.7	56
	Slight problems	25.8	16.2
	Moderate problems	19.4	12.6
	Severe problems	9.2	8.6
	Unable to	6.9	6.6
Usual activities	No problems	28.2	48.4
	Slight problems	32	22
	Moderate problems	18.4	16
	Severe problems	11.6	10.8
	Unable to	9.8	2.8
Pain/discomfort	No problems	52.3	66.8
	Slight problems	26.1	22.3
	Moderate problems	12	06
	Severe problems	08	4.9
	Extreme problems	1.6	0
Anxiety/depression	No problems	66.4	76.2
	Slight problems	14	19.2
	Moderate problems	10.6	2.3
	Severe problems	5.8	2.3
	Extreme problems	3.2	0

Table 4 Analysis of quality of life as measured by EQ-5Q-5L score between cases and control using independent sample *t* test

	Cases (<i>N</i> —31)*	Control (<i>N</i> —42)*	Between group differ- ences in change	<i>p</i> value	95% Confidence interval (lower bound to upper bound)
Mobility	2.61 (1.30)	2.07 (1.31)	0.541	0.043	– 0.078 to 1.161
Self-care	2.19 (1.25)	2.02 (1.29)	0.170	0.288	– 0.433 to 0.773
Usual activities	2.32 (1.24)	1.88 (1.10)	0.442	0.052	– 0.123 to 0.791
Pain/discomfort	1.94 (1.26)	1.69 (1.07)	0.245	0.187	– 0.301 to 0.994
Anxiety/depression	1.74 (1.23)	1.31 (1.01)	0.432	0.029	– 0.012 to 0.877
EQ-5Q-5L index score	– 0.1730 (0.313)	0.1093 (0.301)	– 0.2837	<0.001	– 0.4269 to – 0.1377
Visual analog scale	37.42 (21.1)	59.40 (20.6)	– 21.985	<0.001	– 31.8 to – 12.1

* Mean (standard deviation)

increase in their problems. This could be due to less frequent medication changes in telephonic visits. F Abu Ahmad et al. reported that medication change was made in only 44% of telemedicine visits compared to 59% of in-person visits [10]. This further emphasizes the need to actively find the OPD dropout patients and provide them holistic care.

This study has various strengths and limitations. The primary strength of the study is its uniqueness and raising the

issue of OPD dropout PD patients due to the COVID-19 pandemic. Another strength is the use of matched PD controls attending the OPD and thus directly comparing PD patients who did not attend the OPD versus those who attended it. There are a few limitations in this study, the first being a single-center study with small sample size and lack of non-PD control. Second, one-third of the OPD drop out patients did not participate in the study due to various reasons like

severe illness which make them unable to communicate on phone ($N=4$), mobile network issues in the area, ($N=8$) and changed follow-up in nearby clinics ($N=5$). Therefore, exclusion of these patients could have potentially affect our results and generalization of results is limited. Third, the use of telephonic surveys makes it difficult to capture all the verbal and nonverbal information. Fourth objective assessment of motor and non-motor symptoms and cognitive aspects of the disease could not be obtained due to the telephonic structure of the study. Another limitation is use of generic HRQoL scale rather than PD specific scale such as the PDQ-39 or the SCOPA HRQoL questionnaire which could have led to more pronounced variations.

This study showed that many PD patients are still missing from the OPD for various reasons despite reopening the health facilities. There is a significant worsening of their disease status, which needs urgent interventions. There is an unmet need to actively track these patients and address their issues to provide holistic health care.

Acknowledgements None.

Author contributions AG—study concept and design, acquisition of data, analysis and interpretation, writing of the manuscript. SKN—study supervision, critical revision of the manuscript for important intellectual content. RS—study supervision, acquisition of data, analysis and interpretation, critical revision of the manuscript for important intellectual content.

Funding This study is not funded.

Data availability Not applicable.

Code availability Not applicable.

Declarations

Conflict of interest None.

Standard protocol approvals, registrations, and patient consents Obtained in accordance with appropriate institutional policies.

Additional declarations for articles in life science journals that report the results of studies involving humans and/or animals Not applicable.

Ethics approval Obtained.

Consent to participate Obtained.

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