Quality of life and Concerns of Parkinson’s Disease Patients and their Caregivers during COVID-19 Pandemic: An Indian Study

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Abstract

Objectives: Parkinson’s disease (PD) patients have suffered during the coronavirus disease 2019 pandemic, with worsening of both motor and nonmotor symptoms. We conducted this study to evaluate the quality of life (QoL) and concerns of PD patients and their caregivers.

Methods: The study was conducted in mixed method, where the baseline data was taken by face-to-face interview during the unlock phase of December 2020 to March 2021, when there was no lockdown. This included demography, Hoehn and Yahr (HY) stage, Parkinson’s Disease Questionnaire-8 (PDQ-8), and Parkinson’s Disease Questionnaire for Carer (PDQ-Carer). During the second wave of COVID-19 (April–June 2021), telephonic interview was conducted using Depression, Anxiety Stress Scale- 21 Items (DASS-21), PDQ-8, PDQ-Carer, and open-ended questions regarding their concerns. Results: Compared with the baseline data, PDQ-8 and PDQ-Carer scores showed significant worsening during the second wave. DASS-21 scores had significant correlation with PDQ-Carer and PDQ-8 scores. Female patients reported poorer QoL. Caregivers of non-vaccinated patients had worse PDQ-Carer Strain scores. There was no significant association between worsening of motor symptoms and PDQ-8 and PDQ-Carer scores. More than 80% patients and 70% caregivers reported anxiety and depression. Their concerns were regarding difficulties due to social isolation, restriction of activity, and financial constraints. Additionally, there were worries about patient care, vaccination, and recurrence of the wave. Conclusions: The QoL of both patients and their caregivers were affected by the pandemic. A significant proportion had anxiety and depression, and this correlated with QoL. There were some important concerns on various aspects of the pandemic.

Keywords: Caregivers, concerns, COVID-19, lockdown, Parkinson’s disease, quality of life

Parkinson’s disease (PD) is a chronic neurodegenerative disorder which impairs the motor functioning of the patients along with several nonmotor dysfunctions. Although most of the patients initially respond well to treatment, they gradually become dependent on others as the disease progresses, and the caregivers constitute an important aspect of their management.[1] PD patients have suffered during the coronavirus disease 2019 (COVID-19) pandemic, with worsening of both motor and nonmotor symptoms.[2,3] There is increased anxiety, depression and stress, along with worsening of quality of life during the COVID-19 pandemic in PD patients.[4,5] The waning of the first wave in India signaled respite for them. However, the advent of the second wave heralded further predicaments and threatened to compromise the well-being of the patients. The second wave was even steeper,[6] as it spread rapidly throughout the country and registered numbers four times higher than the first wave. Several of the restraints on daily activities were reinstated, with many parts of the country going into restrictions and lockdowns. Higher rates of COVID-19 cases coupled with the restrictions led to an impairment of lifestyle of the patients. Meanwhile, vaccination drive was rolled out in India and it was opened up for the general public in successive phases.[7]

While this brought some much-needed hope for the people, vaccinating a country with a population of well over a billion is a monumental task.

As the patients struggle with this phase of the pandemic, the caregivers play a crucial role in aiding them tide over the situation. The caregivers themselves are also affected by the pandemic to various extents.[8] Hence, we conducted this study to evaluate the depression, anxiety, stress and quality of life (QoL) of both the PD patients and their caregivers, and understand their concerns associated with the pandemic situation.

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Submitted: 11-Oct-2021 Revised: 24-Jan-2022 Accepted: 27-Jan-2022 Published: 15-Mar-2022

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DOI: 10.4103/aian.aian_905_21
**Material and Methods**

The study was conducted on patients with PD and their caregivers, attending the Movement disorder clinic of the institute. It was a mixed method study conducted over a period of six months. This was part of an ongoing research work of the department with permission from the Institutional Ethics Committee, and informed consent was duly obtained.

**Procedure**

Phase 1: The data for this phase were collected in the movement disorder clinic in face-to-face interview during December 2020 to March 2021 (when there was no lockdown.) A single researcher (SB) was assigned for data collection purpose. This phase has been marked as PhaseP1, that is, the unlock phase between the first and second waves of COVID-19, that had a relaxation or decline in COVID-19 cases. The data consisted of a general descriptive questionnaire [age, sex, duration of the disease, Hoehn and Yahr (HY) stage].\(^{[9]}\) along with Parkinson’s Disease Questionnaire-8 (PDQ-8) and Parkinson’s Disease Questionnaire for Carer (PDQ-Carer) to evaluate the QoL of patients and caregivers, respectively.\(^{[9,10]}\)

Phase 2: During the second wave of COVID-19, a partial lockdown was imposed from April 2021. Hence, between the months of April and June 2021 (designated as PhaseP2), telephonic interview was conducted as per institute protocol for follow-up, to collect the data from the patients and their caregivers. 53 patients were called, out of them 2 were not reachable and 1 denied participating. They were asked for their convenient time and availability for the telephonic interview. They were explained about the purpose of the work and it was conducted on their verbal approval. Here also the previous researcher (SB) was assigned for collecting all the data. The telephonic interview was divided into two halves. In the first half, the general descriptive information was gathered and the respondents were asked about any worsening of motor symptoms of slowness, stiffness, and tremulousness. These were noted according to the subjective assessment by the patients and caregivers. The patients were in ‘on’ state. The onset and duration of action of L-dopa were also enquired. No adjustment of medication was done at the time of the interview. If deemed necessary, they were called separately for such modification. Additionally, the following tools were used – Depression, Anxiety Stress Scale- 21 Items (DASS-21) for both patients and caregivers,\(^{[12]}\) PDQ-8 and PDQ-Carer. Permission was sought from patients and caregivers for another round of telephonic interview in a couple of days to ask some more questions regarding their concerns during this pandemic situation. 43 pairs of patients and caregivers gave verbal consent for the second round of interview, and 15 such pairs were chosen by the method of simple random sampling with the help of random number table.

Construction of the interview schedule: The interview schedule was constructed with the opinion of five subject level experts comprising Neurologists and Neuropsychologists. They were asked about the probable questions and from there the common questions were noted down.

**Tools and Scoring**

**DASS-21** – It measures the emotional states like depression, anxiety, and stress. Each sub-scale contains 7 items and is rated on a 3-point scale ranging from 0 (not applicable) to 3 (very much). Summation of the scores for each sub-scale reflects severity of that emotional state from normal to extremely severe.\(^{[12]}\)

**PDQ-8** – This questionnaire has eight questions on each domain of mobility, activities of daily living, emotional well-being, stigma, social support, cognition, communication, and bodily discomfort. The questions are scored out of 0–4 (0-Never, 1-Occasionally, 2-Sometimes, 3-Often, 4-Always) and a sum score is totaled. The summed score is then divided by total possible score and given as a percentage score out of 100 as a summary index (PDQ-8-SI).\(^{[9,10]}\)

**PDQ-Carer**: The Parkinson’s Disease Questionnaire-Carer (PDQ-Carer) has 29 questions to evaluate QoL in caregivers. This questionnaire has four different domains like Social and personal activities, Anxiety and depression, Self-care and Strain. The score of each item is calculated and converted into 0–100 metric system, where 0 = no problem at all and 100 = worst or maximum level of problem. Finally, the scale score is obtained as the percentage value. The total raw score of each item in this scale is divided by the maximum possible score multiplied by 100. Scores in the range >60–100 for each dimension suggests the deterioration in QoL.\(^{[11]}\)

**Semi-structured Interview Schedule related to concerns** – Four open-ended questions enquired about concerns of the patients and caregivers during the second wave and lockdown.

1. How do you feel about your current condition during the 2nd wave of COVID-19?
2. What are the difficulties you are facing during this situation?
3. Do you have any concern about vaccination?
4. a) What are your worries during this situation pertaining to your health condition? (For the patients)
   b) What are your worries during this situation pertaining to your patient’s management? (For the caregivers)

**Statistical analysis**

Statistical analysis was done by Statistical Package for Social Sciences (SPSS 21). Categorical variables were expressed as frequency (percentage) and continuous variables as mean and standard deviation. These were compared across the groups (age, sex, duration of the disease, HY, COVID status, vaccination status) using Mann–Whitney U test/ Kruskal–Wallis Test as appropriate. The Spearman’s rank correlation coefficient was used to analyze the relationship between continuous variables. Wilcoxon signed-rank test was performed to compare between the QoL data of PhaseP1 and PhaseP2 in both patients and caregivers. A \( P \) value at the level of <0.05 was considered as significant.

Qualitative Analysis – Interviews were interpreted following thematic analysis method. Transcripts were made from the
interviews. They were read, coded, and themes were picked up from them and analyzed accordingly.

**Results**

A total of 50 PD patients and their caregivers were included in the study. Majority of the patients were male (74%), with mean (±SD) age of 56.1 ± 8.96 years. On an average, the caregivers were younger, with a female preponderance. The demographic and disease characteristics are depicted in Table 1. Three patients and six caregivers had contracted COVID-19, but there was no mortality related to it. At the time of the interview, all of them had recovered. Regarding COVID-19 vaccination, 6 patients and 3 caregivers completed both doses, whereas, 18 patients and 16 caregivers received single dose. For the purpose of further analysis, we divided the vaccination status into two groups – vaccinated (including both partial and complete vaccination) and non-vaccinated (who did not receive any dose of the vaccine).

Compared with the baseline PhaseP1 data, both PDQ-8-SI and PDQ-Carer scores showed significant worsening during the second wave/PhaseP2 [Table 2]. Also, during the second wave/PhaseP2, female patients reported poorer QoL (p = 0.02), and caregivers whose patients were non-vaccinated, had worse PDQ-Carer Strain scores (p = 0.036) [Table 3]. DASS-21 scores for depression, anxiety, and stress had significant correlation with all the four dimensions of PDQ-Carer during the second wave/PhaseP2 [Table 4]. DASS-21 scores also showed positive correlation with PDQ-8-SI scores, although, it was statistically significant only for stress. There was positive correlation between PDQ-8-SI and PDQ-Carer scores.

According to DASS-21, more than 80% of the patients reported anxiety and depression [Figure 1]. It was a little lower for the caregivers, still more than 70%. Stress was more frequent in the caregivers. Similarly, the mean scores in DASS-21 were higher in the patients than the caregivers for anxiety and

| Table 1: Characteristics of the patients and caregivers |
|-----------------------------------------------|
| Characteristics                      | Patients (n=50) | Caregivers (n=50) |
|-----------------------------------------------|
| **Age (Years) (Mean±SD)** | 56.1±8.96 | 49.9±12.62 |
| Gender (Male : Female) | 37:13 | 21:29 |
| Hoehn and Yahr stage (Median) | 2.5 | - |
| Duration of Parkinson’s disease (Years) (Mean±SD) | 8.6±4.41 | - |
| COVID-19 positivity status [n (%)] | 3 (6%) | 6 (12%) |
| Vaccination status [n (%)] | Vaccinated Complete | 6 (12%) 3 (6%) |
| Partial | 18 (36%) | 16 (32%) |
| Total | 24 (48%) | 19 (38%) |
| Non-vaccinated | 26 (52%) | 31 (62%) |

| Table 2: Comparison of quality of life measures between the two phases of study |
|-----------------------------------------------|
| Quality of Life                           | PhaseP1 (December 2020-March 2021) (Mean±SD) | PhaseP2 (April-June 2021) (Mean±SD) | P |
|-----------------------------------------------|
| Patient QoL (PDQ-8-SI)                | 43.8±14.31 | 44.9±15.33 | 0.023* |
| Caregiver QoL (PDQ-Carer)              | Social and Personal activities | 31.03±16.79 | 32.4±16.58 | 0.000* |
| | Anxiety and Depression | 38.6±19.53 | 39.9±19.49 | 0.006* |
| | Self-care | 35.1±16.43 | 38.6±16.35 | 0.013* |
| | Strain | 36.01±18.51 | 38.2±19.5 | 0.015* |

*Significance level at P<0.05, PDQ-8-SI=Parkinson’s Disease Questionnaire-8 summary index, PDQ-Carer=Parkinson’s Disease Questionnaire-Carer, QoL=Quality of Life

| Table 3: Correlation of Quality of Life measures with various patient and caregiver characteristics during the second wave/PhaseP2 |
|-----------------------------------------------|
| Quality of Life                          |
| Patient (PDQ-8-SI) | Caregiver (PDQ-Carer) |
|-----------------------------------------------|
| Social and Personal activities | Anxiety and Depression | Self-care | Strain |
|-----------------------------------------------|
| Age | 0.36 | 0.725 | 0.939 | 0.207 | 0.723 |
| Gender | 0.02* | 0.748 | 0.868 | 0.789 | 0.542 |
| Duration of PD | 0.939 | 0.207 | 0.43 | 0.086 | 0.992 |
| HY | 0.596 | 0.757 | 0.389 | 0.328 | 0.92 |
| COVID-19 status | 0.704 | 0.419 | 0.168 | 0.584 | 0.142 |
| Vaccination status | 0.514 | 0.49 | 0.508 | 0.53 | 0.036* |
| Caregiver characteristics | Age | 0.391 | 0.423 | 0.685 | 0.661 | 0.335 |
| Gender | 0.171 | 0.852 | 0.376 | 0.984 | 0.516 |
| COVID-19 status | 0.965 | 0.256 | 0.051 | 0.128 | 0.193 |
| Vaccination status | 0.696 | 0.308 | 0.347 | 0.369 | 0.233 |

*Significance level at P<0.05, HY=Hoehn and Yahr stage, PDQ-8-SI=Parkinson’s Disease Questionnaire-8 summary index, PDQ-Carer=Parkinson’s Disease Questionnaire-Carer
depression, while it was the reverse for stress. However, none of these reached statistical significance. There was significant positive correlation between stress of the patients and their caregivers ($r_s = 0.295, P = 0.037$). There was no significant association of the different patient and caregiver variables with their respective DASS-21 scores.

There was a subjective increase of the motor symptoms of slowness (18%), tremulousness (16%), and stiffness (12%). There was no significant association between worsening of motor symptoms and PDQ-8-SI and PDQ-Carer scores.

The qualitative analysis of the responses to the questions regarding concerns generated the following themes. Few representative examples of responses are listed in Table 5.

**Theme 1 – Difficulties due to social isolation and restriction of activity**

Both the patients and the caregivers faced difficulties due to the restrictions imposed during the second wave of COVID-19. Outdoor activities were minimized and daily routines were disrupted. They found it stressful to deal with the social isolation from the outside world including their friends and other relatives. Telephonic communication was an inferior surrogate, and the use of social media was difficult for the elderly people.

**Theme 2 – Difficulties due to financial constraints**

The caregivers, and patients who were still working, combated financial hardship. While some of them could shift to work-from-home arrangements or retain a steady salary, others found it challenging to maintain a stable source of income. It was difficult to sustain general expenditures of the household and also specifically for patient care.

**Theme 3 – Worries about patient care**

This had two sub-themes –

a. *Worry about worsening of the symptoms* – this stems from two main concerns, unavailability of medicines, and decreased accessibility to rehabilitation measures. The scarcity of medicines was less perceptible than the initial lockdown phases at the beginning of the pandemic in 2020.

b. *Unavailability of transportation to avail medical facilities* – this was a concern for both routine followup and also in case of emergencies.

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**Table 4: Correlation of Quality of Life measures and DASS-21 during the second wave/Phase P2**

| Quality of Life | Depression $r_s$ | Depression $P$ | Anxiety $r_s$ | Anxiety $P$ | Stress $r_s$ | Stress $P$ |
|----------------|------------------|----------------|--------------|-------------|-------------|-----------|
| Caregiver QoL (PDQ-Carer) | Social and Personal activities | 0.692 | <0.001* | 0.704 | <0.001* | 0.695 | <0.001* | 0.300 | 0.034* |
| Anxiety and Depression | 0.805 | <0.001* | 0.811 | <0.001* | 0.649 | <0.001* | 0.358 | 0.011* |
| Self-care | 0.649 | <0.001* | 0.665 | <0.001* | 0.736 | <0.001* | 0.291 | 0.040* |
| Strain | 0.707 | <0.001* | 0.713 | <0.001* | 0.676 | <0.001* | 0.254 | 0.075 |
| Patient QoL (PDQ-8-SI) | 0.220 | 0.124 | 0.145 | 0.316 | 0.335 | 0.017* |

*Significance level at $P<0.05$, DASS-21=Depression, Anxiety Stress Scale-21 Items, PDQ-8-SI=Parkinson’s Disease Questionnaire-8 summary index, PDQ-Carer=Parkinson’s Disease Questionnaire-Carer, QoL=Quality of Life, $r_s$=Spearman’s rank correlation coefficient

**Table 5: Sample excerpts of responses (translated into English) to the semi-structured questionnaire and the corresponding themes**

| Sample Excerpts | Theme |
|-----------------|-------|
| “…Not happy with the fact that we cannot go out and meet others. Sometimes feeling lonely ……” | Difficulties due to social isolation and restriction of activity |
| “… I am out of job for a long time. Things were getting better during the starting month of this year, but again this wave ruined everything……..” | Difficulties due to financial constraints |
| “……these medicines are not always available in our local shops. And the train is also not running. I cannot go to the hospital easily now. I am anxious about this…….” | Worries about patient care |
| “……I am not sure if my patient can take the vaccine. I need to ask the doctor, if a neurological patient can take this vaccine …..” | Concerns regarding vaccination |
| “……what will happen if he gets infected. Already he has this illness, the COVID may make this worse…….” | Frustration and concerns for the recurrence of the wave |
**Theme 4 – Concerns regarding vaccination**

Both patients and caregivers who were still not vaccinated, were concerned about the safety of the COVID-19 vaccines, especially for people with PD. They felt a lack of information on this specific topic. Among those who were already vaccinated, there were concerns about the efficacy of the vaccines.

**Theme 5 – Frustration and concerns for the recurrence of the wave**

There was anxiousness and fear of getting infected with COVID-19 for themselves and their dear ones as the second wave was much larger than the first wave. Sadness and frustration were also evident regarding the recurrence of the wave, especially after a preceding decline of cases when they had thought that the pandemic situation was contained.

**DISCUSSION**

We assessed PD patients and their caregivers during the pandemic, especially regarding their quality of life and various concerns in this situation. PDQ-8 and PDQ-Carer scores showed significant worsening during the second wave. More than 80% patients and 70% caregivers reported anxiety and depression. DASS-21 scores had significant correlation with PDQ-Carer and PDQ-8 scores. Female patients reported poorer QoL. Caregivers of non-vaccinated patients had worse PDQ-Carer Strain scores. There was no significant association between worsening of motor symptoms and PDQ-8 and PDQ-Carer scores. The concerns were regarding difficulties due to social isolation, restriction of activity, and financial constraints. Additionally, there were worries about patient care, vaccination, and recurrence of the wave.

There was significant worsening of QoL of both patients and their caregivers during the second wave of the pandemic. This was in comparison to the preceding trough phase, when people enjoyed more freedom with a very low rate of COVID-19 cases. The surge in the number of cases during the second wave associated with a change in lifestyle from newly imposed restrictions were understandably reflected as a worsening of QoL. Previous studies have also noted a decline in the QoL related to the COVID-19 pandemic, mostly during the initial peaks of transmission and lockdowns.\(^{[14,5,13]}\) At the turn of the year, people were more familiar with COVID-19 than the initial phases, and learned to adapt to the situation such that, with the weakening of the rates of transmission and relaxation of the lockdowns, people gradually returned to a more stable state of daily functioning. We utilized this phase in India as the baseline for our study, and found that despite the aforementioned acquaintance and adaptability, the second wave resulted in a decline of QoL.

Among the various attributes of QoL, gender played an important role, as female patients reported poorer QoL. This resonated with the findings of Suzuki et al.,\(^{[4]}\) which showed worse QoL in female PD patients. Several studies have documented higher prevalence and aggravation of psychiatric symptoms, especially anxiety and depression, in female PD patients during the COVID-19 pandemic.\(^{[14,15]}\) While discussing the higher stress levels in females during COVID-19 pandemic, Al Dhaheri et al.\(^{[16]}\) alluded to the possibility of social and biological variations including a differential activation of brain areas to stressful stimuli. However, the present study could not delve further into the possible reasons for this observation of worse QoL in women. The qualitative analysis also did not reveal any gender-specific theme pertaining to this issue.

The current study shows a high prevalence of depression, anxiety, and stress in the patients and their caregivers, as well as a substantial impact of these aspects of mental health on their QoL, during the second wave of the pandemic. Moreover, both the stress levels and QoL of the patients correlated significantly with that of the caregivers. Hence, it suggests that the events related to the pandemic affected both the patients and their caregivers in a similar detrimental way. Previous studies have recorded an increase in anxiety, depression, and stress during the COVID-19 pandemic, and a correlation of these symptoms with QoL were documented suitably by Shalash et al.\(^{[5]}\) and Suzuki et al.\(^{[4]}\) Interestingly, Hörmann Thomsen et al.\(^{[17]}\) noted an inverse trend, with improvement of Health-related QoL despite an increase in anxiety. The analysis of mood symptoms in PD by Feeney et al.\(^{[15]}\) revealed determinants such as female gender, lower income, reduced exercise, social isolation, and general worry about the future. While Janiri et al.\(^{[14]}\) showed an association of female gender and younger age with worsening of psychiatric symptoms in PD during the pandemic, Kitani-Morii and colleagues found a correlation of depression and anxiety with motor symptoms of PD.\(^{[18]}\) The present study, however, did not find any significant association of DASS-21 scores with age, gender, duration of disease, or HY stage. El Ottmani et al.\(^{[19]}\) also found no effect of age, gender, or HY stage on anxiety and depression. In fact, they did not find any significant impact of confinement on anxiety and depression.

The motor symptoms of bradykinesia, rigidity, and tremor increased in \(<20%\) of patients. This was much lower compared to data from the initial COVID-19 related lockdown from a similar geographic area in India.\(^{[20]}\) We gathered from the open-ended questions that the availability of medications, though still affected, was relatively better during the second wave than the initial lockdown phase. Additionally, patients have now learnt about maintaining a routine of regular activities at home even during the restrictions. In this study, neither deterioration of motor symptoms, nor age, duration of disease or HY stage of PD patients were associated with any worsening of QoL. These findings contradict a previous report by Shalash et al.\(^{[5]}\) which stated a significant correlation of QoL with motor severity. Also, Suzuki et al.\(^{[4]}\) noted worse QoL in patients with longer disease duration. However, similar to the present study, Saluja et al.\(^{[20]}\) did not find any notable influence of age, sex, disease duration, or increase in motor symptoms on QoL. Instead, they demonstrated a significant
effect of non-motor symptoms on QoL. Hence, as evidenced in the current study, anxiety and depression appear to be the stronger correlates of QoL than the motor symptoms.

There was no difference of QoL or depression, anxiety, and stress regarding COVID-19 infection positivity in either the patients or their caregivers. A report by Antonini et al.\(^{[21]}\) remarked on the increase of anxiety in PD patients affected by COVID-19. An elaborate study on COVID-19 survivors by Shah et al.\(^{[22]}\) revealed a considerable impact on their QoL and psychosocial health. In the present study, the significant influence of the second wave in the worsening of depression, anxiety, and QoL in non-COVID-19 positive PD patients, might have masked any additional effect of COVID-19 positivity. However, the very small number of COVID-19 positive cases makes it difficult to arrive at a proper conclusion.

Interestingly, vaccination status of the patients was an important determinant of caregiver QoL, such that caregivers of non-vaccinated patients had worse QoL. While existing data on this topic is limited, it may be postulated that the sense of protection for the vaccinated patients gave confidence to the caregivers and indirectly improved their QoL. Further studies might provide additional data including any contributing factors.

Qualitative thematic analysis revealed some of the chief concerns of the patients and the caregivers during the second wave. Social isolation and limitation of activities led to anxiousness, unhappiness, and stress in coping with the situation. Lessons learnt from the first wave helped in adapting to the recent lifestyle. These uncertain times also paved the way for economic instability. While some had a stable income, others had to struggle to maintain their livelihood. This had direct bearing on patient care. In addition to this, there were worries regarding worsening of patients’ symptoms, mostly arising from concerns about availability of medicines, and accessibility of rehabilitation measures. The supposed higher risk and vulnerability of PD patients to COVID-19 infection during the second wave made them apprehensive. This concern was reiterated by the caregivers. As the country entered into the COVID-19 vaccination era, concerns could be discerned in this regard too. While the non-vaccinated worried about the safety of the vaccines, some of the vaccinated individuals were sceptic regarding the efficacy. Thematic analysis of mood symptoms regarding negative outcomes in PD patients during COVID-19 by Feeney et al.\(^{[23]}\) revealed a lack of physical contact, along with disruption of routines and hindrance to PD management. They also reported fear and worry about the future outcome. The main worries documented by Montanaro et al.\(^{[24]}\) in advanced PD patients were regarding the risk of COVID-19 infection and associated complications in PD, restriction of outdoor activities, and limitation of non-pharmacological treatments and access to hospital. A detailed qualitative study by Anghelescu and colleagues on PD recorded three principal themes – impact of COVID-19 on PD clinical care, activities of daily living, and attitudes and perceptions.\(^{[25]}\)

The study had some limitations. The sample size was small and some of the phone numbers were not reachable, while some of the patients/caregivers declined to answer. An ideal baseline would have been in the pre-COVID era. However, nearly a year has passed since then. Hence, to minimize the effect of disease progression, we selected the preceding trough/unlock phase as the baseline. Another limitation was the lack of data on depression, anxiety, and stress during PhaseP1 to compare with that of PhaseP2. Limitations inherent to the telephonic interview method of data collection over a face-to-face evaluation are also applicable to this study. However, the strength of the study is in its prospective nature, thus, reducing the effect of recall bias.

In conclusion, this study highlights the different aspects of QoL and mental health during this pandemic. QoL of both PD patients and their caregivers worsened during the second wave of the COVID-19 pandemic in India. There was also considerable degree of depression, anxiety, and stress among them, and there was significant correlation between these symptoms and QoL. Female patients and caregivers of non-vaccinated patients had worse QoL. The patients and caregivers showed several concerns regarding the pandemic situation. These concerns give an idea about the perception and difficulties faced by the patients and their caregivers.

**Declaration of patient consent**

The authors certify that they have obtained all appropriate patient consent forms. In the form, the patient(s) has/have given his/her/their consent for his/her/their images and other clinical information to be reported in the journal.

**Financial support and sponsorship**

This work was supported by Indian Council of Medical Research under Grant No. BMS/TF/TRANSNEURO/20143454/SEP15/36/WB/GOVT.

**Conflicts of interest**

There are no conflicts of interest.

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