

Parkinson's Disease and COVID-19: Perceptions and Implications in Patients and Caregivers

The COVID-19 pandemic has resulted in unprecedented disruptions involving every aspect of life across the globe, with the return to normalcy a distant dream. The healthcare sector has undergone dramatic changes to cope with the current needs, and consequently acute care is in the forefront. Attempts to curb COVID-19 have forced countries to be under lockdown, with strict emphases on self-isolation and social distancing. Both factors raise serious concerns about the well-being of patients with chronic illnesses such as Parkinson's disease (PD), as these patients require routine hospital visits for evaluation and dose adjustment. Currently, there is no evidence that patients with PD have a higher risk of contracting COVID-19 or have worse outcomes.¹⁻³

Although healthcare professionals may be aware of this, patients and their caregivers may harbor different perceptions pertaining to these interactions. Furthermore, lockdowns may restrict access to healthcare and physical exercise and may produce additional stress, which could potentially lead to the worsening of motor and nonmotor symptoms in this vulnerable group.

We report our experience at ascertaining the perceptions and implications of COVID-19 in 100 patients with PD and their caregivers who are under follow-up at the National Institute of Mental Health and Neurosciences, Bengaluru, India. Per the hospital directives, patients were contacted via telephone for routine follow-up, and questions pertaining to COVID-19 were asked to clarify misconceptions, if any (Table 1). All participants reported an awareness of COVID-19, with television being the main source of information, and followed preventive measures. Most patients (82%) and caregivers (85%) did not attempt to explore interactions between COVID-19 and PD, as they felt that there was no association between them. However, a small percentage did not explore

TABLE 1. Demographic details, perceptions, and implications of COVID-19 in patients with Parkinson's disease and caregivers

	Patients (n = 100)	Caregivers (n = 100)
Age, y (mean ± SD)	58.06 ± 10.04	44.14 ± 13.79
Gender, M:F (n)	70:30	51:49
Duration of illness, y (mean ± SD)	5.35 ± 3.24	NA
Years of education, (%)		
Illiterate	15	13
Less than 10 years	59	44
More than 10 years	26	43
1. Do you know about the COVID-19 pandemic? (%)		
Yes	100	100
No	0	0
2. How did you find out about the COVID-19 pandemic? (%)		
Television	100	100
Newspapers	38	50
Family members	28	22
Friends	12	10
Doctors	3	4
Social media	0	2
3. Are you following any preventive measures against COVID-19? (%)		
Yes	100	100
No	0	0
3(a). If 3 is "yes," then how?		
Social distancing	100% (100/100)	100% (100/100)
Wearing a mask	37% (37/100)	51% (51/100)
Washing hands	61% (61/100)	60% (60/100)

(Continues)

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TABLE 1. Continued

	Patients (n = 100)	Caregivers (n = 100)
3(b). If 3 is "no," then why?		
Not applicable		
4. Have you tried to find out about any interactions between PD and COVID-19? (%)		
Yes	18	15
No	82	85
4(a). If 4 is "yes," then how?		
Asking family members	66.6% (12/18)	26.6% (4/15)
Asking doctors	33.3% (6/18)	40.0% (6/15)
Searching the internet	0% (0/18)	33.3% (5/15)
4(b). If 4 is "no," then why?		
Don't think there is an association between PD and COVID-19	97.5% (80/82)	95.2% (81/85)
Don't know where to search	2.43% (2/82)	4.7% (4/85)
5. Do you feel that you/your patient is at a higher risk of contracting COVID-19? (%)		
Yes	8	4
No	92	96
5(a). If 5 is "yes," then why?		
Elderly at a higher risk	37.5% (3/8)	50% (2/4)
May have a lower immunity because of PD	62.5% (5/8)	25% (1/4)
Feel there is a higher risk, but don't know why	0% (0/8)	25% (1/4)
6. Are you facing/do you feel your patient is facing any problems because of the COVID-19 pandemic? (%)		
Yes	4	6
No	96	94
6(a). If 6, is "yes," then what?		
Unable to consult a doctor	50% (2/4)	33.3% (2/6)
Unable to procure free supply of medication because of lockdown	50% (2/4)	33.3% (2/6)
Unable to go for walks because of the lockdown	0% (0/4)	33.3% (2/6)
7. Have you noticed any new/worsening of symptoms following the onset of the COVID-19 pandemic? (%)		
Yes	11	10
No	89	90
7(a). If 7, is "yes," then what?		
Increased tremor	45.4% (5/11)	40% (4/10)
Increased stiffness	18.1% (2/11)	0% (0/10)
Increased slowness	0% (0/11)	20% (2/10)
Excessive fatigue	18.1% (2/11)	0% (0/10)
Feeling/appear stressed	9.0% (1/11)	0% (0/10)
Feeling/appear depressed	9.0% (1/11)	30% (3/10)
Reduced sleep	9.0% (1/11)	10% (1/10)
Reduced appetite	0% (0/11)	10% (1/10)
Increased aches and pains	9.0% (1/11)	20% (2/10)

M, male; F, female; NA, not applicable.

interactions as they "didn't know where to look." Perception of a higher risk of contracting COVID-19 was reported in 8% of patients and 4% of caregivers, and both groups implicated the possibility of a lower immunity secondary to PD and old age as risk factors. New problems attributed to the pandemic were reported by a few respondents and were associated with access to healthcare and medication. Finally, the worsening or new symptoms reported or perceived by patients (11%) and caregivers (10%) involved both motor and non-motor symptoms.

These results suggest that most patients and caregivers were well informed and coping well, and a very small proportion were harboring misconceptions with symptomatic worsening. However, our results may be influenced by the relatively lower severity of the pandemic in India, a lockdown that has been in place for barely 3 weeks, and better family support secondary to our sociocultural framework. Owing to this, the


impact of the pandemic may not be completely reflected. Hence, these responses may vary between countries based on the severities of the pandemic and durations of the lockdowns. Misconceptions pertaining to PD and COVID-19 should be clarified by advisories catered toward patients and disseminated through sources that are population and location specific. The long-term consequences of this pandemic on PD is highly uncertain, and timely education and reassurance of patients may help ease the burden. ●

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