

The Impact of COVID-19 on Access to Parkinson's Disease Medication

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ABSTRACT: BACKGROUND: Many countries have implemented drastic measures to fight the COVID-19 pandemic. Restrictions and diversion of resources may have negatively affected patients with Parkinson's disease (PD). Our aim was to examine whether COVID-19 had an impact on access to PD medication by region and income.

METHODS: This study was conducted as part of a survey sent to members of the Movement Disorders Society focusing on access to PD medication globally.

RESULTS: Of 346 responses, 157 (45.4%) agreed that COVID-19 had affected access to PD medication,

while 189 (54.6%) disagreed. 22.8% of high-income and 88.9% of low-income countries' respondents agreed that access to PD medication was affected by COVID-19. 59% of all 'yes' respondents reported increased disability of patients as an impact.

CONCLUSIONS: Access to PD medication is likely to have been affected by COVID-19 and result in deterioration of patients' symptomatic control. Resource-poor countries appear to be disproportionately affected compared to more affluent countries. © 2020 The Authors. *Movement Disorders* published by Wiley Periodicals LLC. on behalf of International Parkinson and Movement Disorder Society.

Key Words: Parkinson's disease; COVID-19; epidemiology; access; medication

COVID-19, caused by the SARS-CoV-2 virus, was first detected in December 2019 in Wuhan, China. The virus has rapidly spread and infected millions globally since. The World Health Organization declared it a public health emergency and a pandemic on March 11, 2020¹. Many governments have implemented drastic measures to curb the viral spread and heavily restrict human movement both within and between countries.

Parkinson's disease (PD) is the second most common neurodegenerative disease globally². Although effective symptomatic treatment for PD patients is firmly established in many regions of the world, the restrictions and diversion of resources precipitated by COVID-19 may have negatively affected PD patients. This study aimed to assess the impact of COVID-19 on access to PD medication globally according to region and wealth by surveying healthcare providers.

Methods

This sub-study formed part of a wider global survey of health professionals involved in the care of PD patients. A survey was sent by email to all members on the Movement Disorders Society (MDS) mailing list (approximately 10,000 recipients) on June 4, 2020, and again on June 23, 2020. Responses received up to and including the 8th July 2020 are presented here.

The wider survey was written in English and consisted of 14 questions. It was reviewed in draft and modified by the MDS Epidemiology Study Group (ESG) and then endorsed by the MDS. It seeks to investigate access and availability to PD treatment in different countries, including symptomatic drug treatment;

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non-oral therapies such as deep brain stimulation (DBS), apomorphine and levodopa/carbidopa intestinal gel (LCIG); unregulated and naturally growing therapies; and non-pharmacological treatments, including physiotherapy, occupational and speech and language therapy.

The present sub-study included two questions that focused on the impact of COVID-19. Respondents were asked whether their patients had difficulty obtaining their regular medication due to the COVID-19 pandemic and to elaborate on the impact that had, including increased disability, hospitalization, mortality, no clinical impact, and a free text space for unlisted impacts. The specific wording of these two survey questions can be found in the Supplementary Information.

Data Analysis

Responses to the two survey questions were tabulated and graphically illustrated using Microsoft Excel. Free text comments that were relevant to the study objectives were reviewed.

Responses were first organized according to the geographical regions used by the United Nations Statistics Division (UNSD), which are based on continental regions further subdivided into subregions and intermediary regions to obtain greater homogeneity in sizes of population, demographic circumstances, and accuracy of demographic statistics³. For the purpose of this report, countries in Eastern Africa, Middle Africa, Southern Africa, and Western Africa were classified as Sub-Saharan Africa.

Responses were then reorganized according to the country income classifications for the World Bank’s 2020 fiscal year. This classification divides countries’ economies into four income groups - high-, upper-middle, lower-middle and low income. This takes into account a country’s Gross National Income (GNI) per capita, which can be affected by economic growth, inflation, exchange rates, and population⁴. Classification thresholds are also adjusted for inflation annually using the Special Drawing Rights (SDR) deflator⁴.

Responses that did not provide a country or job title or listed “patient” as job title were excluded.

Results

Participants/Demographics

The questionnaire had a total of 354 respondents and 346 of the responses were included. Of these participants, 317 (91.6%) were doctors. The largest number of responders were recorded from India, 32 of 346 (9.2%); Brazil, 26 of 346 (7.5%); and the United States of America, 21 of 346 (6.1%). A complete list of responding countries is available in Supplementary Information.

Impact of COVID-19 Pandemic on Access to Regular PD Medication

Of the 346 respondents who answered the question on whether their patients experienced difficulty obtaining regular PD medication as a result of the

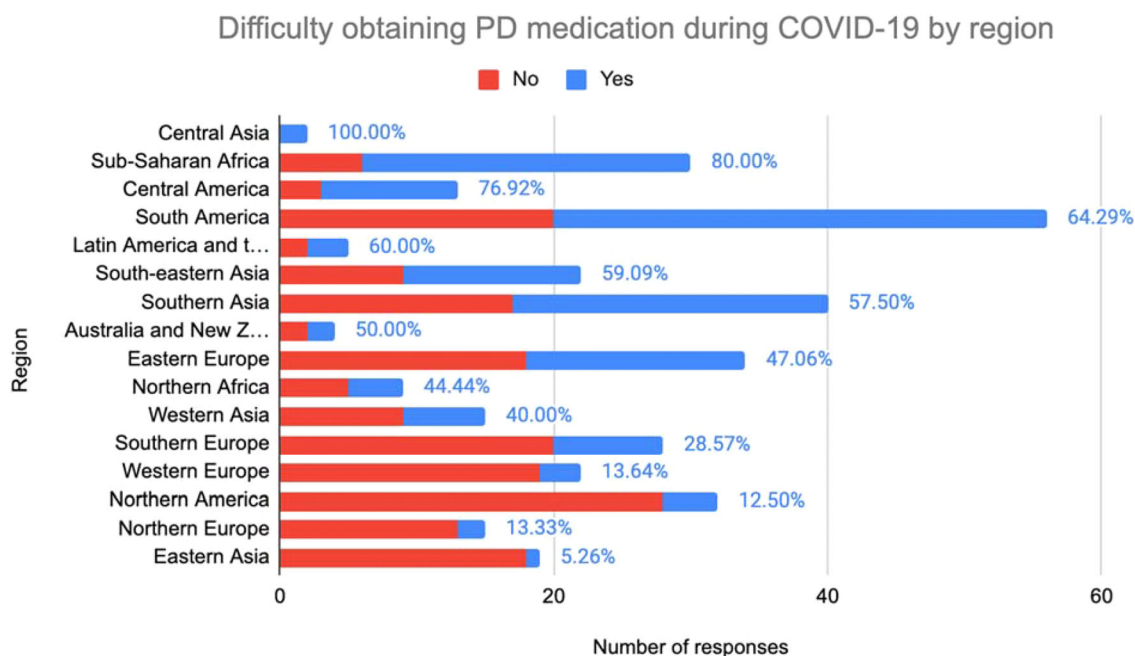


FIG. 1. Difficulty Obtaining PD Medications during the COVID-19 outbreak by UNSD region. The number and proportion of “yes” responses are indicated by blue bars and figures, respectively, whereas red bars indicate “no” responses. [Color figure can be viewed at wileyonlinelibrary.com]

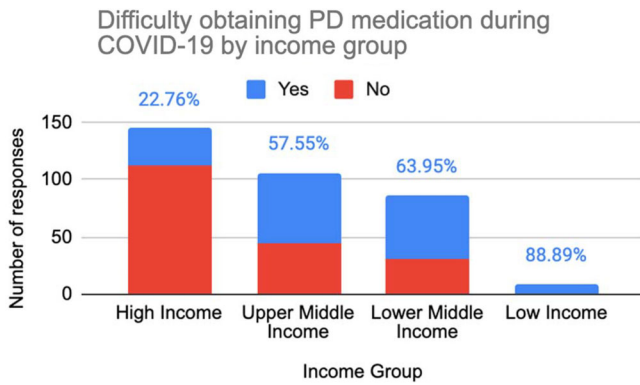


FIG. 2. Difficulty Obtaining PD Medication during the COVID-19 outbreak by National Income Group. The number and proportion of “yes” responses are indicated by blue bars and figures, respectively, whereas red bars indicate “no” responses. [Color figure can be viewed at wileyonlinelibrary.com]

COVID-19 pandemic, 157 (45.4%) responded “yes” whereas 189 (54.6%) said “no”.

Of the 157 “yes” responses, 134 (59.0%) reported increased disability, 19 (8.4%) reported increased hospitalization, 6 (2.6%) reported increased mortality and 68 (30.0%) felt that the COVID-19 pandemic had no obvious clinical impact on PD patients.

Qualitative examination of the free text responses revealed that COVID-19 had caused a decrease in the availability of medication in countries (responses from Kenya, Bangladesh, Ghana, and the United States of America) for various reasons such as transportation disruptions, lower economic development of an area and financial issues (at both individual and system levels).

Impact of COVID-19 on Access to Regular PD Medication by UNSD Region

Of the 16 recognized UNSD regions included in this study, 8 regions had 50% or more respondents who answered “yes” to whether their patients experienced difficulty obtaining regular PD medication during the COVID-19 pandemic (Fig. 1).

Impact of COVID-19 Pandemic on Access to Regular PD Medications by World Bank Classification by Income

The proportion of respondents who answered “yes” to whether their patients experienced difficulty obtaining regular PD medication due to the COVID-19 pandemic was 88.9% among low, 64.0% among low-middle, 57.6% among upper-middle and 22.8% among high income countries (Fig. 2).

The proportion of responses reporting increased disability, increased hospitalization, increased mortality and no obvious clinical effect were compared across income groups. An increasing trend of disability reported from high- (37.2%) to low- (100.0%) income

countries was evident. A graph of this comparison can be found in Supplementary Information.

Discussion

This global survey of healthcare workers involved in treating PD patients was conducted at the peak of the COVID-19 pandemic. It provides preliminary evidence that COVID-19 likely increased health inequity with respect to treatment of PD, with the poorest countries and their patients appearing to suffer most. Although patients in high-income countries, including those in East Asia, North America, and North West Europe, were relatively well served at this time (<15% adverse responses), this is not the case in other regions of the world. Large parts of Asia, Africa, and Latin and South America appear to have been disproportionately affected. This is particularly concerning because at the time of the survey, many of these regions were in the early stages of their COVID-19 experience.

Several recent studies have reported the association between PD and increased severity of COVID-19 infection⁵⁻⁷. Other studies have examined the impact of COVID-19 on patients, such as increased anxiety from social isolation and fear of infection and reduced physical activity^{5,8}. A recent study investigating the effects of COVID-19 reported by PD patients indicated reduced quality of healthcare, including worsening symptoms and disruption to medication access⁹. To our knowledge, ours is the first study to examine the impact of COVID-19 on access to PD medication globally by surveying healthcare professionals.

Many governments implemented “lockdowns” in an attempt to control the spread of COVID-19. Such lockdowns have disrupted care for chronic conditions, including PD⁹⁻¹². Access to PD medication may have been impacted by the closing of routine clinical space, faltering delivery systems, or, in some settings, the inability to access dispensaries or pay for medication. Furthermore, countries have channeled efforts toward fighting COVID-19¹³. This may have impacted the availability of healthcare professionals supporting PD patients. For example, many elective surgical procedures, such as DBS, and non-urgent infusion therapies such as LCIG and apomorphine have been delayed^{7,9}.

A large number of respondents indicated that their patients have experienced increased disability due to reduced access to medication. This concurs with information reported by other studies of worsening clinical PD symptoms amidst COVID-19, including motor^{9,13-15}, non-motor^{9,13,15} and neuropsychiatric symptoms^{9,13}. Although PD is a highly treatable condition, disruptions in provision and access to treatment may worsen disability and increase adverse outcomes as the pandemic continues. It is essential that the PD community devise ways

to reduce impact to patients over the coming months and years.

At the patient level, part of the response has been a greater reliance on telemedicine. Even before COVID-19, the use of telemedicine for PD care was increasing^{16–20}. A recent report highlighted the role of telemedicine for chronic neurological diseases in improving access to care, convenience, comfort, confidentiality and in reducing infection during the COVID-19 pandemic²¹. The MDS has also recently developed a guide on telemedicine for movement disorders clinics²². Although telemedicine is valuable for follow-up of stable patients, it has limitations for initial assessment and diagnosis. For some patients, such as those with cognitive impairment, impulse control behaviors, and psychosis, its appeal and utility are less. Importantly, technology should try to balance inequities in care, but there is some evidence that this may not be the case⁹. Furthermore, issues around access in the COVID-19 era extend way beyond difficulties around clinical consultations. The focus should be at the systems level to ensure the supply and dispensing of medication are reinstated effectively.

Limitations

Our study had several limitations. First, the overall response rate was low (approximately 3.5%). High-income countries provided a disproportionate number of responses (n = 145) compared to low-income countries (n = 9), which might affect the accuracy of our results from low-income countries. This may be due to a smaller representation of low-income countries on the MDS members register, access to the Internet at present, or competing priorities such as actively fighting the pandemic. Therefore, it is important to develop methods to better understand the impact in these regions and provide support.

Second, as a quantitative survey, our questionnaire was unable to fully explore how patients had been affected. Respondents could select from four options or a free text field if the options were inapplicable. An option for respondents to make further comments was provided. However, this was not always completed.

Third, our study was unable to distinguish increased disability associated with access to PD medication from other confounding factors. Stress is known to significantly affect PD manifestation^{23,24}. It has been reported that the COVID-19 pandemic has placed PD patients at an increased risk of anxiety from self-isolation and fear of infection^{14,25}, which could contribute to increased disabilities independent of access to PD medication.

Conclusion

Our results offer preliminary data that the COVID-19 pandemic has affected PD patients' access to regular

medication. COVID-19 has diverted resources away from chronic conditions toward the fight against COVID-19 in many countries. Resource-poor countries seem to be disproportionately affected compared to their affluent counterparts. ■

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References

1. World Health Organisation. WHO Director-General's opening remarks at the media briefing on COVID-19 - 11 March 2020 [Internet]. 2020. <https://www.who.int/dg/speeches/detail/who-director-general-s-opening-remarks-at-the-media-briefing-on-covid-19-11-march-2020>. Accessed July 24, 2020.
2. Tysnes OB, Storstein A. Epidemiology of Parkinson's disease. *J Neural Transm*. 2017;124:901-905.
3. United Nations Statistics Division. UNSD — Methodology. 2020. <https://unstats.un.org/unsd/methodology/m49/>. Accessed July 24, 2020.
4. The World Bank. World Bank Country and Lending Groups. 2020. <https://datahelpdesk.worldbank.org/knowledgebase/articles/906519-world-bank-country-and-lending-groups>. Accessed July 24, 2020.
5. Bhidayasiri R, Virameteekul S, Kim J-M, Pal PK, Chung S-J. COVID-19: An early review of Its global impact and considerations for Parkinson's disease patient care. *J Mov Disord*. 2020 May 31;13(2):105-114.
6. Antonini A, Leta V, Teo J, Chaudhuri KR. Outcome of Parkinson's disease patients affected by COVID-19. *Mov Disord*. 2020 May 28;35(6):905-908. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7267273/>. Accessed July 24, 2020.
7. Fasano A, Cereda E, Barichella M, et al. COVID -19 in Parkinson's disease patients living in Lombardy, Italy. *Mov Disord*. 2020 Jun 26;35(7):1089-1093. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7300944/?report=abstract>. Accessed July 24, 2020.
8. Helmich RC, Bloem BR. The Impact of the COVID-19 pandemic on Parkinson's disease: Hidden sorrows and emerging opportunities. *J Parkinsons Dis*. 2020 Apr 3;10(2):351-354. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7242824/>. Accessed July 24, 2020.
9. Brown EG, Chahine LM, Goldman SM et al. The effect of the COVID-19 pandemic on people with Parkinson's disease. *medRxiv*. Cold Spring Harbor Laboratory Press; 2020 Jul. <https://www.medrxiv.org/content/10.1101/2020.07.14.20153023v1>. Accessed August 2, 2020.
10. Ghosh A, Gupta R, Misra A. Telemedicine for diabetes care in India during COVID19 pandemic and national lockdown period: Guidelines for physicians. *Diabetes Metab Syndr Clin Res Rev*. 2020 Jul 1;14(4):273-276. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7129346/?report=abstract>. Accessed July 24, 2020.
11. Mauro V, Lorenzo M, Paolo C, Sergio H. Treat all COVID 19-positive patients, but do not forget those negative with chronic diseases. *Intern Emerg Med*. 2020 Jun 9;1-4. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7282471>. Accessed July 24, 2020.
12. Benaque A, Gurruchaga MJ, Abdelnour C, et al. Dementia care in times of COVID-19: Experience at Fundació ACE in Barcelona, Spain. *J Alzheimer's Dis*. 2020 Jun 12;76(1):1-8. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7369075/?report=abstract>. Accessed 24 July 2020.
13. Schirinzi T, Cerroni R, Di Lazzaro G, et al. Self-reported needs of patients with Parkinson's disease during COVID-19 emergency in Italy. *Neurol Sci*. 2020 Jun 1;41(6):1373-1375. <https://ncbi.nlm.nih.gov/pmc/articles/PMC7196180/?report=abstract>. Accessed July 24, 2020.
14. Zipprich HM, Teschner U, Witte OW, Schönenberg A, Prell T. Knowledge, attitudes, practices, and burden During the COVID-19 pandemic in people with Parkinson's disease in Germany. *J Clin Med*. 2020 May 29;9(6):1643. <https://www.mdpi.com/2077-0383/9/6/1643>. Accessed Jul 24, 2020.

15. Prasad S, Holla VV, Neeraja K, et al. Parkinson's disease and COVID-19: Perceptions and implications in patients and caregivers. *Mov Disord.* 2020 May 8;35(6):912-914. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7264599/>. Accessed July 24, 2020.
16. Ben-Pazi H, Browne P, Chan P, et al. The promise of telemedicine for Movement Disorders: An interdisciplinary approach. *Current Neurology and Neuroscience Reports.* 2018 Apr 13;18:26. <https://doi.org/10.1007/s11910-018-0834-6>.
17. Schneider RB, Biglan KM. The promise of telemedicine for chronic neurological disorders: the example of Parkinson's disease. *Lancet Neurol.* 2017 Jul;16(7):541-551. <https://pubmed.ncbi.nlm.nih.gov/28566190/>. Accessed July 24, 2020.
18. Dorsey ER, Deuel LM, Voss TS, et al. Increasing access to specialty care: A pilot, randomized controlled trial of telemedicine for Parkinson's disease. *Mov Disord.* 2010 Aug 15;25(11):1652-1659. <https://doi.org/10.1002/mds.23145>.
19. Abdolahi A, Scoglio N, Killoran A, Dorsey ER, Biglan KM. Potential reliability and validity of a modified version of the Unified Parkinson's Disease rating scale that could be administered remotely. *Park Relat Disord.* 2013 Feb 1;19(2):218-221. <http://www.prd-journal.com/article/S1353802012003847/fulltext>. Accessed July 24, 2020.
20. Miele G, Straccia G, Moccia M, et al. Telemedicine in Parkinson's disease: How to ensure patient needs and continuity of care at the time of COVID-19 pandemic. *Telemed e-Health.* 2020 Jul 13. <https://www.liebertpub.com/doi/10.1089/tmj.2020.0184>. Accessed July 24, 2020.
21. Bloem BR, Dorsey ER, Okun MS. The Coronavirus Disease 2019 Crisis as Catalyst for Telemedicine for Chronic Neurological Disorders. *JAMA Neurology.* 2020 Apr 24;77(8):927-928. <https://jamanetwork.com/journals/jamaneurology/fullarticle/2765073>. Accessed July 24, 2020.
22. Papa SM, Brundin P, Fung VSC, et al. Impact of the COVID-19 pandemic on Parkinson's disease and Movement Disorders. *Mov Disord.* 2020 May 16;35(5):711-715. <https://doi.org/10.1002/mds.28067>.
23. Hemmerle AM, Herman JP, Seroogy KB. Stress, depression and Parkinson's disease. *Exp Neurol.* 2012 Jan;233(1):79-86. <https://pubmed.ncbi.nlm.nih.gov/22001159/>. Accessed July 24, 2020.
24. Zach H, Dirkx MF, Pasma JW, Bloem BR, Helmich RC. Cognitive stress reduces the effect of levodopa on Parkinson's resting tremor. *CNS Neurosci Ther.* 2017 Mar 1;23(3):209-215. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5324662/?report=abstract>. Accessed July 24, 2020.
25. Salari M, Zali A, Ashrafi F, et al. Incidence of anxiety in Parkinson's disease during the coronavirus disease (COVID -19) pandemic. *Mov Disord.* 2020 May 21;35(7):1095-1096. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7273007/>. Accessed July 24, 2020.

Supporting Data

Additional Supporting Information may be found in the online version of this article at the publisher's web-site.

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Author Roles

(1) Research Project: A. Organization, B. Execution, C. Conception; (2) Statistical Analysis: A. Design, B. Execution, C. Review and Critique; (3) Manuscript: A. Writing of the First Draft, B. Review and Critique
J.L.Y.C.: 1A, 1B, 2A, 2B, 2C, 3A
Z.H.K.G.: 1A, 1B, 2A, 2B, 2C, 3A
C.M.: 2C, 3B
C.M.T.: 2C, 3B
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