

**VIEWPOINT**

Challenges in Parkinson's Disease Care—In Light of the COVID-19 Pandemic

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Over the past two years, the coronavirus disease (COVID-19) pandemic has exposed two of the ugliest faces of health care: an unprecedented flood of misleading information and health care disparities. Whether intentionally misleading or genuinely ignorant, mask futility theory, conspiracy theories, and anti-vaccine campaigns have sprung up around the world and have created major obstacles to infection control from the very beginning of COVID-19. The pandemic has also revealed dramatic disparities in access to health care between countries, communities, and socioeconomic classes: as of July 2020, the US mortality rate for COVID-19 by race per 10,000 nearly doubled from 2.3 for white patients to 5.6 for black and Hispanic patients and 4.3 for Asian patients.¹ During the pandemic, some communities provided the best care for critically ill patients, while in others, even oxygen supply was at risk. These two health care issues that remain to plague us after the pandemic has subsided have, in fact, existed long before the pandemic. As movement disorder specialists, we realize that infodemics and health care disparities constitute a major challenge that requires sociopolitical consensus in the treatment of Parkinson's disease (PD). Here, we discuss the current status of these problems and briefly introduce the results of a recent survey conducted by the Korean Parkinson's Disease Association and Seoul National University Hospital on 356 patients with parkinsonism and 132 caregivers from January to February 2022.

First, we have our fair share of misinformation that hampers proper management in PD. The first is levodopa phobia. The COVID-19 vaccination phobia is not new to us. Levodopa is the most effective drug to treat PD to date, but fear of increasing doses, the myth that taking the drug will speed up PD progression,

and misinterpretation of data on levodopa-induced dyskinesia lead to poor compliance.^{2,3} In our survey, the 488 respondents were asked to rate their subjective trust in levodopa treatment on a scale of 0 to 10 points. The average trust rated was 5.56 points, and 58.2% gave 5 points or less; reasons for the low score (multiple responses) were concerns about the development of tolerance following long-term use (53.1%), fear of side effects (43.4%), and concerns about speeding up the progression of parkinsonism due to taking levodopa (29.5%).

Another danger underlying this phobia is the growing amount of misleading information available on the internet. Stamelou et al.⁴ reviewed the accuracy of movement disorder-related videos on YouTube and found that only 34% could be considered to present true movement disorders. In Korea, our team previously evaluated the contents of 138 Korean YouTube videos. Only 65.9% contained accurate information on PD, and ironically, videos with misleading content gained higher popularity both in terms of the number of views and likes.^{5,6} Regarding the source of information on anti-parkinsonian treatment, the most common responses in this year's survey were doctors (88.1%) and the internet (78.7%), but the reliability of the internet (5.63) and other patients (4.83) was higher than that of doctors (4.24). Similarly, regarding the source of information on novel treatments for parkinsonism, both the selection rate and evaluated reliability were higher for the internet (84.4%, 5.79) and other patients (75.4%, 4.96) than doctors (69.5%, 2.84). We need to be aware that patients are lured into flashier misinformation.

Furthermore, patients often seek traditional medicine, more generally complementary and alternative medicines (CAM). However, scientifically well-designed studies are lacking, and

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CAM researchers often fail to mention the adverse effects that may have occurred during clinical trials.^{7,8} For instance, acupuncture is a popular CAM intervention in Korea; also, favored by PD patients. However, patients were not blinded to treatment, and data for 9 dropouts of 35 patients in the treatment group were not provided in the results section, possibly biasing the results in the favorable direction.⁹ Still, the author appeared on Korean national TV claiming that the benefit was recognized by a Western medical journal. In a survey conducted nationwide in 2014 by the Korean Movement Disorders Society (KMDS), 42% answered that they would perform bee venom acupuncture (BVA) even when they were told that BVA is still experimental without proven safety and benefit. In our 2022 survey, 51.6% of respondents answered that they had tried traditional medicine or acupuncture for the purpose of treating parkinsonism. Regarding the source of information on these alternative medicines, the top three sources were the internet (58.4%), other patients (55.7%), and doctors (55.5%), but in terms of trust, the internet (4.33) and other patients (3.48) were rated much higher than doctors (1.92). Given that doctors generally give negative comments about CAM, a possible explanation for this discrepancy is that patients refer to their doctors for opinions about CAM but often do not trust the negative responses and still rely on CAM. This would be a challenge for movement disorders specialists, who require a social-wide campaign to change patients' perceptions.

The second ugly face in the challenges of COVID-19 and PD is health care disparity. Lim et al.'s¹⁰ review of PD in the Western Pacific region shows that there are countries where even the most basic levodopa treatment is not universally available. Korea is a homogeneous society with universal access to national health insurance and the most advanced medical care, but social inequality exists and makes a difference in patient care. The KMDS surveyed what PD patients and caregivers need in 2017.¹¹ The top priority was new treatment for PD, and the second was burden of cost for treatment. PD patients become economically weaker not only because of medical costs but also because of productivity loss, which affects those with lower socioeconomic status. The cost does limit choice by patients. For example, financial burden was the second most important reason for being reluctant to receive deep brain stimulation (DBS) in our center.¹² In this year's survey, 76.0% answered that it was difficult to financially bear the cost of hospitalization and/or surgery; the rate was 71.9% of the 249 respondents with 13 years of education or longer, and it increased to 80.3% among the 239 respondents with 12 or fewer years of schooling. There is also a geographic disparity. In Korea, there is a nearly threefold difference between Seoul and nonmetropolitan areas in the number of doctors per 1,000 population. Elderly individuals, who are at high risk for PD,

tend to live in rural areas, and aging, PD itself, socioeconomic problems, and vulnerability to various medical comorbidities impede patient mobility. In our survey, the ratio of residents in metropolitan and nonmetropolitan areas was similar: 50.2% to 48.8%. However, while 78.4% of the metropolitan residents answered that they were being treated at hospitals in their residential areas, the rate dropped to 32.9% among the nonmetropolitan residents. This health care disparity in nonmetropolitan areas is especially true for advanced treatment options such as DBS. Engagement in clinical trials is limited. Those with geographic and socioeconomic limitations are more vulnerable to harm from disinformation, such as "traditional medicine," and knowledge gaps result in delays in diagnosis. Meanwhile, telemedicine is emerging as an alternative to these geographic disparities, especially in regard to the management of chronic diseases during pandemics. In a survey of clinicians at centers specializing in PD across Germany, 97.5% said they had experienced cancellations of patient visits during the COVID-19 pandemic.¹³ A total of 77.5% of respondents said that they offered phone counseling to patients during the pandemic and that this option was "broadly accepted" by patients.¹³ Research on home-monitoring systems to help evaluate movement disorders remotely is also being actively conducted.¹⁴ In our survey, 93.4% of participants responded that they were in favor of introducing telemedicine for parkinsonian disorders. While telephone consultations and prescriptions were temporarily permitted during the COVID-19 outbreak, additional discussions are needed to establish the scope and methodology of the introduction of telemedicine in Korea.

These health care disparities not only limit patient access to optimal pharmacological and surgical treatment options in terms of physical and financial aspects but also limit access to nonpharmacological management and social support. In an earlier survey of 476 patients and caregivers conducted by the Korean Parkinson's Disease Association, 31.5% said they wanted rehabilitation but could not do it at all due to cost problems, and 18.1% said they could not do as much as they wanted. When asked about the status of disability diagnosis, 27.3% said they did not know about the disability diagnosis system. Ignorance of such social security systems could deprive patients of the opportunity to receive adequate nonpharmacological aids for the problems they face. To solve this problem, the KMDS is actively conducting promotional activities related to PD through YouTube, websites, booklets, and media. We believe that these campaigns should continue through diverse routes inside and outside the clinic, taking into account the characteristics of the patient group, of which a large number are elderly and socially disadvantaged.

In summary, PD is no different from COVID-19 in its treatment challenges, in that our health care professionals are facing

infodemics and health care disparities in the management of both. We confirmed once again that levodopa phobia, which is a classic issue in our field that corresponds to the recent mask futility and vaccine conspiracy theories, still hinders the treatment of PD and that patients are lured to sources of medical misinformation. Geographic and socioeconomic disparities still deprive large numbers of vulnerable patients of opportunities for timely treatment. We are sure that these two issues resonate at the global level. There are many medical issues to cogitate in caring for patients with PD, and it is time to recognize the social issues of infodemics and health care disparities within our society.

Ethics Statement

Not applicable

Conflicts of Interest

Kyung Ah Woo: Employment: Seoul National University Hospital.

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