

The Impact of the COVID-19 Pandemic on Parkinson's Disease Patients in the Rural Midwest: A Mixed Methods Study

Maria Andrea Garcia Elizondo B.A.

Juliana de Almeida Cardoso Ph.D.

Lorraine Edwards M.D.

See next page for additional authors

Follow this and additional works at: <https://newprairiepress.org/urjhs>



Part of the [Health and Medical Administration Commons](#), [Mental and Social Health Commons](#), [Nervous System Diseases Commons](#), and the [Virus Diseases Commons](#)

This Research Paper is brought to you for free and open access by New Prairie Press. It has been accepted for inclusion in Undergraduate Research Journal for the Human Sciences by an authorized administrator of New Prairie Press. For more information, please contact cads@k-state.edu.

The Impact of the COVID-19 Pandemic on Parkinson's Disease Patients in the Rural Midwest: A Mixed Methods Study

Authors

Maria Andrea Garcia Elizondo B.A.; Juliana de Almeida Cardoso Ph.D.; Lorraine Edwards M.D.; and
Jermaine Francis Jr., B.A.

The Impact of the COVID-19 Pandemic on Parkinson's Disease Patients in the Rural Midwest: A Mixed Methods Study

Abstract

The COVID-19 pandemic brought challenges for individuals with Parkinson's disease (PD). This concurrent mixed methods study explored the perceived pandemic's impact on the quality of life and functional ability of individuals with PD in the rural Midwest. Thirty-one participants with Parkinson's disease ($M_{\text{age}}=73.48$, $SD_{\text{age}}=7.18$) completed the quantitative stage, which included measures of self-reported daily functioning. There was no statistically significant difference in self-reported daily functioning between participants who perceived they have had COVID and those who did not, $t(29)=-.27$, $p=.46$. Twenty-two participants completed semi-structured interviews that explored perceived quality of life. Thematic analysis identified five themes: symptom overlap, varied pandemic reactions, health literacy challenges, dimensions of isolation, and diverse perceptions of physical and emotional well-being. Findings highlight the multifaceted characteristic of quality of life, the need for comprehensive interdisciplinary approaches, peer support, and community-based programs to address the complex needs of PD patients.

Keywords: Parkinson's disease, COVID-19, rural health, quality of life, mixed methods.

Introduction

The COVID-19 pandemic, resulting from the SARS-CoV-2 virus, has impacted the lives of millions, with the World Health Organization (WHO) claiming there have been over 777 million confirmed cases as of May 25, 2025 (WHO, 2025). While there has been increasing research on the biological mechanisms underlying COVID (e.g., Kirubananthan et al., 2021), there is still relatively limited information on this novel disease and its many psychosocial implications on individuals with Parkinson's disease (Kumar et al., 2021). COVID and COVID sequelae ("long COVID") symptoms range widely and include fatigue, brain fog, dizziness, anosmia, respiratory impairment, chest pain, heart palpitations, depression, and anxiety (Jarrott et al., 2021), which can potentially increase the risk for reduced health outcomes for individuals with neurodegenerative disorders.

Studies suggest that the pandemic exacerbated some of the challenges faced by Parkinson's disease patients. For example, the social isolation imposed by COVID-19 was shown to worsen the severity of Parkinson's symptoms and negatively impact quality of life (Subramanian et al. 2020). Additionally, chronic stress, which was experienced by many during the pandemic, has been shown to exacerbate motor deficits (Diwakarla et al., 2019). Furthermore, social distancing, in particular, was shown to have a significant negative impact on the daily functioning of PD patients, especially as it disrupted important routines such as exercise, which is known to improve quality of life in patients suffering from neurodegenerative disorders (Yogev-Seligmann & Kafri, 2021). Notably, loss of independence and declines in daily functioning are well-documented challenges in Parkinson's disease, even outside of the context of the pandemic, with a reduced ability to perform activities of daily living (ADLs) significantly impacting quality of life and caregiver burden (Leroi et al., 2012; Horne & Lincoln, 1998).

This study addressed critical gaps in the existing literature by examining the intersection of Parkinson's disease, COVID-19 infection, and pandemic-related disruptions. The authors hypothesized that individuals with Parkinson's disease who perceived themselves as having contracted COVID-19 would demonstrate lower scores on functional outcome measures. Furthermore, the qualitative component of this study explored the broader psychosocial and health-related variables associated with COVID-19 exposure within this vulnerable patient population.

Methods

A concurrent exploratory mixed methods design was used to better understand the relationship between COVID-19, the pandemic, and daily functioning and quality of life in individuals with Parkinson's disease. The study had the following inclusion criteria: participants needed to be at least 19 years old, they needed to have a diagnosis of Parkinson's disease, be able to provide informed consent, and be currently receiving neurological care. The ability to provide informed consent was determined by clinical staff at the neurological clinic through physical and mental examinations, as well as through evaluation of medical records. Recruitment occurred via posters and promotional materials distributed at a local neurology clinic located in a rural area in the Midwest. All study procedures were approved by the ethics review committee, and written informed consent was obtained from all participants prior to enrollment. Additionally, confidentiality and privacy were maintained throughout data collection and analysis. For the qualitative stage, interviews were conducted in English at the clinic.

Quantitative Stage

A total of 31 participants ($M_{\text{age}}=73.48$, $SD_{\text{age}}=7.18$; range: 63-94) completed the quantitative portion of the study. Participants were all Caucasian, and most identified as males ($n=25$). Physical severity of PD as reflected by motor deficits was assessed using the current version of the Movement Disorder Society – Unified Parkinson's Disease Rating Scale (MDS-UPDRS) Part III motor examination (MDS, 2019), administered by a qualified neurological provider at the clinic. The MDS-UPDRS Part III has demonstrated strong internal consistency, with Cronbach's alpha values reported around 0.93 (Goetz et al., 2008), and its use is well-established and recommended in PD research and clinical practice (Bouça-Machado et al., 2022). This evaluation informed the provider's determination of disease stage using the Modified Hoehn and Yahr Scale.

The Hoehn and Yahr Scale, (Hoehn & Yahr, 1967), which is commonly used to determine the stage of Parkinson's disease progression based on the severity of motor dysfunction, has been modified to include stages 1.5 and 2.5 to account for intermediate disease progression (Goetz et al., 2004). All participants were evaluated as part of their clinical care and given a score on this scale. The Modified Hoehn and Yahr scale is a single-item ordinal scale that has demonstrated reliability in prior studies (Goetz et al., 2004). Scores range from 1 to 5, with higher scores indicating increased motor dysfunction. Participants ($N=29$) scores in this sample ranged from 1 to 4 ($M=2.35$, $SD=0.74$)

Functional status was assessed using two validated instruments: the Katz Index of Independence in Activities of Daily Living (ADL) and the Lawton-Brody Instrumental Activities of Daily Living Scale (IADL). The Katz ADL scale has shown strong internal consistency, with a

Cronbach's alpha of 0.86 (Shelkey & Wallace, 1999), while the Lawton-Brody IADL Scale reports Cronbach's alpha values between 0.85 and 0.91 (Graf, 2008). Scores were summed to create a composite functional score, allowing evaluation of both basic and instrumental activities of daily living. Although these scales were not originally developed specifically for individuals with PD, they have been widely used to assess functional status in older adults and individuals with neurodegenerative conditions, including PD (Horne & Lincoln, 1998; Leroi et al., 2012). . The reliability and validity of these measures in similar populations support their use in this study to evaluate functional ability. Scores were summed to create a composite functional score, allowing evaluation of both basic and instrumental activities of daily living. Composite scores created could theoretically range from zero to 14, with higher scores indicating greater functioning. For the current sample (N=31), scores ranged from 9-14 (M=13.52, SD= 1.03), indicating that most participants had relatively few issues with functioning.

Qualitative Stage

For the qualitative portion, semi-structured interviews were conducted with 22 participants, all of whom had also completed the quantitative stage. A phenomenological theoretical framework was used for the qualitative stage, which focused on understanding the lived experiences and perspectives of PD patients in relation to the COVID-19 pandemic. Interviews explored participants' perceptions of their health, experiences with COVID-19, and the psychosocial impact of both COVID-19 and the pandemic as a whole. Interviews were completed in person and audio-recorded and transcribed using Otter.ai. Data was analyzed using thematic analysis to identify key patterns and themes. Two independent coders, both undergraduate students, conducted the qualitative analysis to increase validity.

Results

Thirty-one participants with Parkinson's disease ($M_{age}=73.5$, $SD_{age}=7.2$) completed the quantitative stage. Participants were categorized into a COVID group, composed of individuals who believed they had not contracted COVID-19 ($N=14$), and a non-COVID group, composed of individuals that believed they had never had COVID ($N=17$). The mean self-reported functional ability score for the COVID group was 13.5 ($SD=1.2$), while the mean for the non-COVID group was 13.6 ($SD=.76$). The subsequent t-test comparing the means revealed no statistically significant difference in self-reported functional ability between the groups, $t(29)=-.27$, $p=.46$.

The thematic analysis of the qualitative data yielded the following five main themes: (1) symptom overlap between Parkinson's disease and COVID-19, leading to challenges in symptom management; (2) diverse initial reactions to the COVID-19 pandemic, reflecting varying levels of risk awareness and concern; (3) health literacy challenges; (4) the multidimensional impact of isolation on perceived quality of life; and (5) diverse perceptions of physical and mental/emotional wellbeing.

Symptom Overlap Between Parkinson's Disease and COVID-19

Symptom overlap between Parkinson's Disease and COVID-19 was a notable theme ($N=4$). One participant voiced their concern saying *"How much is the original three fatigue factors and how much is leftover COVID, I don't know."* The similarities between some COVID symptoms and PD symptoms made it difficult for patients to identify if they were experiencing PD "flare ups" or potentially "long COVID".

Diverse Initial Reactions to the COVID-19 Pandemic

Many participants (N=10) remembered experiencing concern and fear at the start of the pandemic, when the severity of the situation was not yet known. One of these participants said they were “*Somewhat scared; for my health and supporting my family*”. This quote illustrates the multifaceted nature of these initial reactions, with fear stemming from many different reasons, like concern for not being able to financially support one's family, or anxiety over contracting the disease and experiencing health issues. Others (N=6) claimed not to have been worried, “*I didn't expect it to be as bad as it was*”. This indifference could very well have stemmed from a lack of knowledge or could have been a way to cope with a difficult situation.

Health Literacy Challenges

There seemed to be a decreased self-efficacy in understanding health related information (N=7). Some of it was related to the pandemic and some of it was regarding their Parkinson's Disease. One participant said, “*I didn't quite know how to take medical professionals telling me not to get the vaccines*”. This points to a broader sense of confusion and concern with healthcare messaging that shaped their decisions and overall experience.

Multidimensional Impact of Isolation on Perceived Quality of Life

Nearly half of the participants (N=10) claimed to have no issues with the social distancing and isolation that took place during the pandemic, with one stating “*It didn't really affect us too much, cause we live on a farm*”. However, the same number of participants (N=10) noted their lives felt disrupted by the isolation, with one person sharing, “*I didn't go to funerals, important ones.*”. The perception of the impact this isolation had on their quality of life varied. Seven participants claimed it had no impact on their quality of life, five claimed it had some

impact, and four claimed it had a significant impact.

Diverse Perceptions of Physical and Mental/Emotional Wellbeing

Eight participants said they felt positive about their physical and mental/emotional wellbeing, with one of them saying *“I feel pretty good. I mean, I’ve had Parkinson’s for 19 years and a lot of people still don’t know I have it”*. An additional eight participants were split, feeling somewhat positive about certain aspects and negatively about others. One of the participants who felt split mentioned, *“I guess it bothers me because I know I might not be able to do what I want to do.”*. Finally, six participants noted they felt negatively about their wellbeing. One of these participants said, *“I imagine that I do [have depression/anxiety]. I’d really bet. I’m not on any antidepressants. But I bet you there’s depression there if you ever diagnosed or checked it out. I bet ... runs in the family.”*

Collectively, these findings support the belief that quality of life among individuals with Parkinson’s disease is influenced not only by functional ability, but also by complex biopsychosocial factors. Additional illustrative quotes for each theme can be found in the appendix.

Discussion

While the quantitative analysis did not reveal significant differences in functional scores between participants who believed they had contracted COVID-19 and those who did not, the qualitative findings provided important insights into the broader psychosocial challenges faced by this patient population during the pandemic and post-pandemic. The qualitative findings highlight that functional ability is only one facet of overall quality of life in individuals with Parkinson’s disease. Notably, the results emphasize the need for targeted health literacy

interventions to support individuals with PD in navigating their healthcare, properly evaluating information, making informed decisions, and effectively advocating for their needs.

Additionally, the qualitative analysis indicated the value of an interdisciplinary, holistic approach to care, which has become even more critical in the aftermath of the pandemic. To address these challenges, consistent with previous research (e.g. Bland et al., 2021), we recommend group activities that promote physical, psychological, and social well-being, such as community-led exercise classes, peer support groups, and educational workshops. These initiatives may foster social connection, empowerment, and improved health outcomes. Collectively, these findings support the need for multifaceted, patient-centered interventions that address all of the diverse dimensions of wellbeing for individuals with PD. Future research should explore the implementation and evaluation of these approaches to enhance quality of life in this population.

As the pandemic progressed, research into alternative opportunities to support this patient population increased. Our findings and recommendations are similar to those from Bland et al. (2021), which found that home-based digital dance programs emerged as an accessible and beneficial alternative. These programs offered physical, cognitive, and emotional benefits, despite social isolation. Participants reported improvements in balance, mobility, mood, and sleep, with higher engagement linked to more positive outcomes. These findings highlight the potential of remote technology-mediated interventions to complement traditional care models for PD.

In addition to dance-based interventions, telerehabilitation programs emerged as a critical strategy for maintaining therapeutic support for individuals with Parkinson's disease during the COVID-19 pandemic. Bianchini et al. (2022) demonstrated that providing physiotherapy,

occupational therapy, and speech therapy virtually was not only possible, but also safe and effective in improving motor function, balance, and overall quality of life among patients with mild to moderate Parkinson's disease. These findings further illustrate the value of an adaptable variety of approaches to increase daily functioning and quality of life in face of pandemic-related restrictions, while reinforcing the need for holistic hybrid care models, potentially beyond the pandemic.

Limitations and Future Directions

Several limitations of this study should be noted. First, the quantitative sample size was small, and predominantly Caucasian males, which limits the generalizability of the findings to the broader population of individuals living with Parkinson's disease. A larger, more diverse sample would be necessary to strengthen the validity and applicability of the results. Further research should investigate a diverse sample with the potential of informing cultural adaptations to our recommendations. Additionally, the sample was biased toward individuals with preserved cognitive and functional abilities, since participation required sufficient cognitive functioning to complete the assessments. As a result, individuals with cognitive impairment or dementia were excluded, limiting our ability to capture the experiences of those at more advanced stages of the disease who may face distinct challenges. Future research may explore longitudinal interventions that can be adapted for this population. Additionally, research also needed on adapting psychosocial interventions in different settings, such as community-based groups. Recruitment from a single neurology clinic may have also introduced selection bias, as participants were already engaged in specialized care and their experiences may not reflect those of individuals without the same access to neurological services.

Acknowledgements

This study was generously funded by the Excelsior Grant, which made its completion possible.

References

- Bianchini, E., Onelli, C., Morabito, C., Alborghetti, M., Colombo, R., Cossu, G., ... & Montesano, A. (2022). Feasibility, safety, and effectiveness of telerehabilitation in mild-to-moderate Parkinson's disease. *Frontiers in Neurology*, 13, Article 909197. <https://doi.org/10.3389/fneur.2022.909197>
- Bland, J., Gauthier, M., Leventhal, D., & Pacchetti, E. (2021). Home-based dance programs for people with Parkinson's disease during the COVID-19 pandemic: Access, engagement, benefits, and limitations. *Frontiers in Neurology*, 12, Article 678124. <https://doi.org/10.3389/fneur.2021.678124>
- Bouça-Machado, R., Fernandes, A., Ranzato, C., Beneby, D., Hipólito Nzwalo, & Ferreira, J. J. (2022). Measurement tools to assess activities of daily living in patients with Parkinson's disease: A systematic review. *Frontiers in Neuroscience*, 16. <https://doi.org/10.3389/fnins.2022.945398>
- Diwakarla, S., Finkelstein, D. I., Constable, R., Artaiz, O., Di Natale, M., McQuade, R. M., Lei, E., Chai, X., Ringuet, M. T., Fothergill, L. J., Lawson, V. A., Ellett, L. J., Berger, J. P., & Furness, J. B. (2019). Chronic isolation stress is associated with increased colonic and motor symptoms in the A53T mouse model of parkinson's disease. *Neurogastroenterology & Motility*, 32(3). <https://doi.org/10.1111/nmo.13755>
- Goetz, C. G., Poewe, W., Rascol, O., Sampaio, C., Stebbins, G. T., Counsell, C., Nir Giladi, Holloway, R. G., Moore, C. G., Wenning, G. K., Yahr, M. D., & Seidl, L. (2004). *Movement Disorder Society Task Force report on the Hoehn and Yahr staging scale:*

Status and recommendations The *Movement Disorder Society Task Force on rating scales* for Parkinson's disease. *Movement Disorders*, 19(9), 1020–1028.

<https://doi.org/10.1002/mds.20213>

Goetz, C. G., Tilley, B. C., Shaftman, S. R., Stebbins, G. T., Fahn, S., Martinez-Martin, P., ...

LaPelle, N. (2008). Movement Disorder Society-sponsored revision of the Unified Parkinson's Disease Rating Scale (MDS-UPDRS): Scale presentation and clinimetric testing results. *Movement Disorders*, 23(15), 2129–2170.

<https://doi.org/10.1002/mds.22340>

Graf, C. (2008). The Lawton Instrumental Activities of Daily Living (IADL) Scale. *The American Journal of Nursing*, 108(4), 52–62.

<https://doi.org/10.1097/01.NAJ.0000314810.46029.74>

Horne, M., & Lincoln, N. B. (1998). Everyday activities in Parkinson's disease: Relationship with disease characteristics and self-rated disability. *Disability and Rehabilitation*, 20(9), 373–377.

Jarrott, B., Head, R., Pringle, K. G., Lumbers, E. R., & Martin, J. H. (2022). “LONG COVID”—A hypothesis for understanding the biological basis and pharmacological treatment strategy. *Pharmacology Research & Perspectives*, 10(2), 1–10.

<https://doi-org.hclproxy.hastings.edu/10.1002/prp2.911>

Kirubananthan, L., Illuri, R., Rajendran, R., & Chandrasekaran, P. R. (2021). Mechanism and transmission routes of COVID-19. *Environmental and Health Management of Novel Coronavirus Disease (COVID-19)*, 65–88.

<https://doi.org/10.1016/b978-0-323-85780-2.00013-5>

Kumar, A., Narayan, R. K., Pranav Prasoon, Kumari, C., Kaur, G., Kumar, S., Maheswari

Kulandhasamy, Kishore Sesham, Vikas Pareek, Faiq, M. A., Pandey, S. N., Singh, H. N., Kant, K., Shekhawat, P. S., Raza, K., & Kumar, S. (2021). COVID-19 Mechanisms in the Human Body—What We Know So Far. *Frontiers in Immunology*, 12.

<https://doi.org/10.3389/fimmu.2021.693938>

Leroi, I., McDonald, K., Pantula, H., & Harbishettar, V. (2012). Cognitive impairment in Parkinson disease: Impact on quality of life, disability, and caregiver burden. *Journal of Geriatric Psychiatry and Neurology*, 25(4), 208–214.

<https://doi.org/10.1177/0891988712464823>

Long COVID or Post-COVID Conditions. (2022). CDC.

<https://www.cdc.gov/coronavirus/2019-ncov/long-term-effects/index.html> Shelkey, M.,

& Wallace, M. (1999). Katz Index of Independence in Activities of Daily Living (ADL). *The Hartford Institute for Geriatric Nursing, NYU College of Nursing*. Subramanian, I., Farahnik, J., & Mischley, L. K. (2020). Synergy of pandemics-social isolation is associated with worsened Parkinson severity and quality of life. *Npj Parkinson's Disease*, 6(1).

<https://doi.org/10.1038/s41531-020-00128-9>

Yogev-Seligmann, G., & Kafri, M. (2021). Covid-19 social distancing: Negative effects on people with parkinson disease and their associations with confidence for

self-management. *BMC Neurology*, 21(1). <https://doi.org/10.1186/s12883-021-02313-6>

Appendix

Themes	Main Codes	Main Sub-Codes	Example	Frequency
Multifaceted Initial Reactions	Initial Feelings			
		Concern/Fear	<i>"Somewhat scared. For my health and supporting my family."</i>	10
		Not worried	<i>"I didn't expect it to be as bad as it was."</i>	6
	Initial Thoughts			
		Conspiracy/Political	<i>"Like we were getting screwed. I think it was set up... [Who do you think set it up?] Democrats. Just more bullshit."</i>	4
Dimensions of Isolation	Experience			
		No issues	<i>"It didn't really affect us too much cause we live on a farm."</i>	10
		Disruption	<i>"Well, yeah, that affected me. I didn't go to funerals, important ones."</i>	10
	Impact on QoL			
		None	<i>"You understand my lifestyle. Social distancing is normal. I was a farmer and still able to farm. We just don't have neighbors."</i>	7
		Some	<i>"Maybe a little bit when the family was gathering..."</i>	5

		Significant	<i>"I'm a people person. I like to be around people. So it did make a difference that we couldn't see our friends and family as much..."</i>	4
--	--	-------------	--	---

Physical & Mental/Emotional Well-being	Perception of physical & mental / emotional health			
		Positive	<i>"I feel pretty good. I mean, I've had Parkinson's for 19 years and a lot of people still don't know I have it."</i>	8
		Split	<i>"I guess it bothers me because I know I might not be able to do what I want to do. You know?"</i>	8
		Negative	<i>"I imagine that I do [have depression/anxiety]. I'd really bet. I'm not on any antidepressants. But I bet you there's depression there if you ever diagnosed or checked it out. I bet ... runs in the family."</i>	6
Perceived Health Literacy	Varied opinions & understanding of vaccines		<i>"I didn't quite know how to take medical professionals telling me not to get the vaccines."</i>	7
Symptom Overlap	Confusion		<i>"How much is the original three fatigue factors and how much is leftover COVID, I don't know."</i>	4

Table 1: Summary of themes identified through Thematic Analysis with illustrative quotes.