ORIGINAL RESEARCH

"A whole day, I might not say a word": Responses to the Pandemic by People with Parkinson's

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Abstract

Background: The widespread SARS-CoV-2 or COVID-19 virus accounted for approximately 2.5 million deaths worldwide. Parkinson's Disease (PD) is a progressive movement disorder of the central nervous system in which the loss of dopamine results in motor and nonmotor symptoms. Stress can exacerbate PD symptoms. The purpose of this study was to examine the lived experiences of persons with Parkinson's disease during the COVID-19 pandemic. ***Research Question:*** The research question, "what is it like to live with Parkinson's Disease during the COVID-19 pandemic?" guided this study. Examining the subjective lived experiences and meanings of living with PD during the COVID-19 pandemic will advance nursing science by providing insight into the long-term effects as well as the care and services needed to improve patients' health and well-being. ***Methodology:*** This study employed a phenomenological approach to examine the subjective lived experiences and meanings of living with PD during the COVID-19 pandemic. A sample of 14 participants with PD were interviewed. Colaizzi's seven steps were used for data analysis and methods to ensure trustworthiness were employed. ***Results:*** Three themes emerged: (1) pandemic effects, (2) adaptations, and (3) stress and coping. Categories representing the pandemic's effects included restrictions, the effects of restrictions on physical and mental health, and precautions. Categories representing adaptations included being intentional about contact, activity adaptations, and relocation. Categories representing stress and coping included stress effects, coping, and stress and the pandemic. ***Limitations:*** This was a small homogeneous sample. All were white and educated individuals, recruited from two service organizations in Texas, and unaware of their PD staging. At the same time, everyone with PD experience different symptoms and stress responses creating heterogeneity. ***Conclusion and Recommendations:*** Based on the findings of this study, a holistic assessment should be conducted during routine visits with people with PD. Nurses and other health care professionals should be aware that a pandemic may have a holistic effect on the well-being of persons with PD necessitating assessment beyond the classic symptoms of tremor, bradykinesia, rigidity, and postural instability.

Keywords: central nervous system diseases; brain diseases, Parkinson's Disease

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Introduction

Parkinson's Disease (PD) is a chronic, progressive neurological disorder that affects the motor system and is commonly recognized by the classic symptoms of tremor, bradykinesia, rigidity, and postural instability (Parkinson's Foundation [PF], 2021). Approximately ten million people worldwide live with PD (PF, 2021). Currently, there is no cure and individualized treatment is tailored to symptomatology. Treatment may include medications, surgery, and lifestyle modification in which emerging evidence suggests that exercise may help delay disease progression (Ahlskog, 2011; Goodwin et al., 2008; Paillard et al., 2015).

The pressures of daily life can substantially impact health concerns. Specifically, stress can have a negative effect on persons with PD resulting in anxiety and depression, and can also exacerbate PD symptoms (Sulzer et al., 2020). The global COVID-19 pandemic may further compound stress and exacerbate symptoms given lockdowns, strict guidelines, fear or anxiety of leaving one's home, and disruption of pre-COVID daily routines. People with PD experience uncertainty, for example, medication efficacy which may affect their ability to function. The uncertainty of the course of this condition under this pandemic scenario presents unique challenges for nurses, other healthcare professionals, and organizations serving people with PD. Therefore, a comprehensive assessment of the individual beyond the classic PD symptoms is essential.

Data regarding the effects of the pandemic should be considered in relation to PD. According to Johns Hopkins University's tracking system (2021), over 2.9 million people have died worldwide from the widespread SARS-CoV-2, the virus that causes COVID-19. While a PD diagnosis does not increase a person's risk of developing COVID-19 (Ferini-Strambi, 2020), advanced age and chronic illness, such as PD, place an individual in a high-risk group (Zhang et al., 2020). Coronavirus affects the respiratory system and because people with PD are at an increased risk for developing pneumonia, they are categorized as a vulnerable population, further validating them to be at high risk (Zhang et al., 2020). A study conducted by the University of Iowa Health Care (2020) revealed a 30% increase in mortality among people with PD compared with people without (n = 80,000). The American Parkinson's Disease Association [APDA] (2020) summarized current literature about PD and the COVID pandemic. Key takeaways from this report include older individuals with PD experience increased mortality; those without a diagnosis of COVID-19, but in lockdown, experience increasing motor and nonmotor symptoms; and persons with PD, who contract COVID-19, report sequala of either worsening of or new PD symptoms (APDA, 2020). It is within this context that the researchers were prompted to conduct a study for the purpose of examining the lived experience of persons with PD during the COVID-19 pandemic. The research question, "*What is it like to live with PD during the COVID-19 pandemic?"* guided this study.

Literature Review

The literature highlighted the effects of the COVID-19 pandemic on persons with Parkinson's Disease and its global impact. Literature originated in Italy (Antonini et al., 2020; Schirinzi et al., 2020), Egypt (Shalash et al., 2020), India (Prasad et al., 2020), Morrocco (El Otmani et al., 2021), Iran (Salari et al., 2020), and the United States (Brown et al., 2020; Subramanian et al., 2020). Since the pandemic, people with PD reported increased motor (Brown et al., 2020; Prasad et al., 2020), non-motor (Prasad et al., 2020) and autonomic symptoms, and problems with sleep (Brown et al., 2020). People with PD also experienced challenges completing activities of daily living (Brown et al., 2020). Their psychosocial functioning resulted in limited activity and social and exercise engagement (Shalash et al., 2020) further exacerbating their symptoms (Brown et al., 2020). Isolation secondary to COVID-19 stay-at-home restrictions resulted in loneliness and correlated with decreased quality of life (QoL) and increased PD symptomatology (Subramanian et al., 2020). Reduced cognition, mood, (Brown et al., 2020) fatigue, anxiety (Antonini et al., 2020; Prasad et al., 2020; Salari et al., 2020; Shalash et al., 2020), depression, and stress (Helmich et al., 2020; Prasad et al., 2020; Shalash et al., 2020) were reported. On the contrary, El Otmani and colleagues (2021) found that a six-week confinement did not result in a statistically significant change in depression and anxiety scores among 50 Moroccan people with PD. Older people with PD and those who have been diagnosed with PD for a longer time were more susceptible to COVID-19 and experienced greater mortality (Antonini et al., 2020), while younger people with PD reported worsening of PD symptoms (Schirinzi et al., 2020). In response to worsening motor symptoms, levodopa doses were increased (Antonini et al., 2020).

Methods

Design

This study employed a phenomenological approach to examine the subjective lived experience and meanings of living with PD during the COVID-19 pandemic. Phenomenology "seeks to describe the essence of a phenomenon by exploring it from the perspective of those who have experienced it" (Teherani et al., 2015, p. 91). This is an appropriate methodological design to reveal the essence of the lived experience (Creswell, 2013).

Sample

Purposive and snowball sampling were used to identify participants who have PD and were willing and able to share their experiences of living with PD during the COVID-19 pandemic. The inclusion criteria were: individuals 30 years of age or older, able to speak, read, and write English, have a diagnosis of Parkinson's Disease, have Internet access or an electronic device with a camera and microphone, demonstrate understanding of the study purpose and expectations, and able to provide consent to participate in this online research study.

Setting and Data Collection

Following Institutional Review Board approval and written informed consent, in-depth, semi-structured interviews were conducted online using Zoom, a videoconference platform, and were digitally recorded. All participants, except for one who completed a phone interview, joined the Zoom meeting online from their home. A camera allowed the researchers to observe nonverbal cues for clarifications, such as gestures and facial expressions. Demographic questions and an interview guide consisting of open-ended questions elicited rich thick descriptions and an opportunity for participants to share their experiences. Questions were not limited to the effects of the pandemic on PD symptoms. The interview questions were also broadly stated to elicit the full effect of the pandemic on their lived experiences (Appendix A). Probes were used to clarify the meaning of responses and encourage in-depth descriptions. Trust and rapport were initiated and maintained throughout the interview process. Every effort was made to assist the participants to feel comfortable discussing pandemic experiences and share insights. Furthermore, all participants were informed that they did not have to answer any question they did not want to answer and could stop the interview at any time. Data collection continued until recurring themes emerged.

Data Analysis

A systematic approach to data analysis, congruent with the phenomenological design, was used to analyze the participant transcripts following Colaizzi's (1978) seven steps of data analysis. The process will be described to demonstrate rigor in the data analysis process. The initial step began with reading and re-reading the transcripts in their entirety multiple times to understand the essence of the participants' experience. Next, significant statements were then extracted related to the phenomenon being studied. Meanings were then derived from the significant statements formulated, categorized, and clustered into themes of commonly shared perceptions by the participants. Following clustering, the themes were described and supported by participant quotes. Findings were shared with a subset of participants for validation to ensure accurate representation of the phenomenon and, based on the emergence of new and relevant participant data, were included in the final analysis.

All of the interviews were audio-recorded using a primary and back-up digital recording and the interview transcripts were recorded verbatim and verified for accuracy. Researchers simultaneously listened to the audio recording, read the transcript and corrected errors as needed. The process of coding involved two methods whereby the primary investigator manually coded the interview transcripts while the second author utilized qualitative data analysis software, NVivo version 11. Furthermore, notes were made along the margins. The dual use of digital coding (NVivo) and traditional paper, pens, and highlighting rendered greater insight, producing a rigorous and robust analysis. The files were reviewed independently and the researchers came together for ongoing discussion to establish intercoder reliability. The data analysis process was cyclical whereby the research team met frequently to discuss insights to support the continuous process of reflecting and understanding to further elicit meaning (Creswell, 2013). Categories and themes were validated by participants and both researchers. The findings section was emailed to three participants who read and confirmed an accurate representation and no revisions were required.

Hard copies of the informed consent and demographic data were stored in a locked file cabinet to which only the researcher had access. To ensure confidentiality, participant data were de-identified and stored separately from the coding list, and no names were included in the transcripts. All data were saved on a password-protected computer with firewall security and shared electronic files were stored on a password-protected program. Salient participant quotes, with no identifiable data, were included to support the themes that emerged.

Findings

Fourteen people (n = 14) with PD were recruited from organizations serving people with PD. The purposive sample included five men and nine women all of whom were Caucasian and had some college education. The average age was 70.5 and ranged from 60-82 years. The average length of time since diagnosis was nine years with a range of two to 19 years.

Three themes emerged from the data: (1) pandemic effects, (2) adaptations, and (3) stress and coping. Categories representing the pandemic's effects included lifestyle restrictions, the effects of restrictions on physical and mental health, and precautions. Categories representing adaptations included being intentional about contact, activity adaptations, and relocation. Categories representing stress and coping included stress effects, coping, and stress and the pandemic.

Pandemic Effects

Lifestyle Restrictions

Most participants identified ways the pandemic affected them. However, five indicated, "it doesn't occupy my thought very much," "it really hasn't changed my lifestyle very much at all probably because we still go out a lot," and "it hasn't affected me in any special way." Restrictions imposed by the pandemic included event and activity limitations, socialization and physical contact with friends and family, and travel. Activities in which participants no longer engaged in were listening to live music, going to museums, restaurants, movie houses, churches, beauty shops, parties, wine tastings, and shopping trips. Parkinson-specific activities such as support groups and Rock Steady Boxing, a non-contact boxing program for people with PD, were no longer offered in person. "I really miss not being able to exercise in a group setting. I find it so much more motivating than going by myself," stated one participant. Activity limitations were evident in statements such as, "thrown havoc into our calendar" and "forc[ed] out of [my] routine." The lack of social interactions and physical contact with friends and family members were shared. "I'm clearly worried about my wife's mother (a resident in an independent living setting). We really prefer to see her more often," said one participant. Another said, "my husband is afraid of exposing me to them (family members). And they're afraid" and "she (niece) can't (drop by with dinner) anymore because she

works as a teacher and they don't want to infect me." Interactions with grandchildren were especially missed and verbalized as, "Oh, my gosh, why am I going to start crying? It's just bringing back the memories of not being able to see my grandkids for like a month when I was used to seeing them every day. Another participant shared, "not seeing people, not being able to see my friends . . . 'It's great to see you', I miss that." Lack of physical contact was evident:

> When we hit the door, I'll try not to cry, he (participant's grandson) just wants to hug me. 'Now, you can't do that. You see Papa might get sick', I have to tell him. And a four-year-old said, 'I can't hug you, Papa?', because he has trouble understanding.

Other participants recalled, "I'm alone, haven't hugged anybody in a very long time, since March" (eight months since the time of the interview). "I am a people person. I'm a hugger. I have a tree across the street that I hug, but that's about-- and my wife of course," and "I'm in hug deficit."

Travel to visit family and for pleasure had been limited. "We don't travel right now because of the COVID danger" said one participant. Another responded, "I have a daughter and three grandchildren on the East Coast. My son's in Boulder. And we were always seeing them every month or two. I haven't seen them since February." One participant was angry that she had to cancel a trip: "I had a trip planned with my best friend from college to fly to Seattle, and we're renting a Volkswagen camper there and we were taking a trip around the Olympic Peninsula." Two participants had traveled out of state to visit family and while participants clearly missed traveling, the cost savings was acknowledged, "we've been able to save money because we're not traveling."

Precautions

All but one participant mentioned the need to take precautions: "Wearing the mask is something that you just automatically do now," "I wear gloves," and "I'm being cautious, washing hands and staying away from contact with other people." A participant stated, "I'm hibernating more." Another recognized that by wearing a mask "we're not just protecting ourselves, but we're protecting others." For one participant, setting boundaries for social distancing when others did not comply was difficult, "well, I didn't know how to tell him" (to social distance).

Health

Participants recognized the pandemic's effect on their physical and psycho-social health. Other participants felt that the pandemic had not affected their Parkinson's and one person described a benefit. "I haven't, to my knowledge, at least, experienced any difficulties with the Parkinson's that I think are related to the pandemic." The pandemic had a positive impact on one participant's health, "it's beneficial for me to be inside and stay isolated a lot because it allows me to regulate my medicines more thoroughly and do the exercise routines."

Physical complaints were related to lack of activity. "I find myself sitting in a chair longer than I would normally," "I can tell it's affected how limber I am or how flexible I am because I haven't had as much exposure to exercise," and "I don't have as much energy because I'm not out and about as much as I was before," said three participants. Some participants felt their Parkinson's symptoms were worse:

> (The pandemic) kind of took over my Parkinson's because I kept getting weaker . . . I'm so worn out. Completely worn out.
>
> (The pandemic) affected the left side . . . I couldn't play the piano . . . my fingers wouldn't push the keys down.

Others experienced stiffness, achiness, sore joints, and more frequent freezing episodes.

Several psycho-social effects were identified. "I got one word, boring" stated one participant. Two people recognized changes in thinking: "keeping my mind straight (is the greatest challenge)" and "I was doing, trying to remember Dr. Oz's (television talk-show host) mandate to work your brain. That went away." Participants felt the stay-at-home directives were "depressing or irritating" and made them "mad and/or angry." Anxiety related to being "intentional that everything you do in protecting yourself, your family" and the potential long-term economic impact on retirement pensions. Another participant explained, "I'm not used to living in fear being conscientious about doorknobs, elevator buttons." Participants realized that they were at greater risk for negative outcomes if they contracted COVID which caused fear, "It's kind of scary" (being at greater risk because of PD). Isolation was an identified concern illustrated by the following, "I'm alone," "I'm lonely," and "a whole day, I might not say a word." One participant weighed the risks and benefits:

> I think it's better to take the chance to go out and do the things that I want to do instead of isolating myself and making sure that I won't get sick just by isolating myself because I think that's very depressing, just to be isolated.

Changes imposed by the pandemic were highlighted by one who said, "the biggest struggle is not feeling normal. Yeah, it just doesn't feel normal in my life." At the time of the interviews, two participants were reaching out to their providers regarding symptoms of anxiety and depression.

For some participants, health care appointments were delayed while others met with providers virtually or face-to-face. "Both of those got moved back, so eye, teeth (appointments). My physical was moved back, too." Another participant stated, "my doctor wanted to see me through telemedicine," however, the participant insisted, "I need to see her. I want her to see my body. I want to see how I'm doing." Elective procedures such as cataract surgery had been delayed indefinitely.

Adaptations

Participants shared how they adapted to the pandemic including being intentional about staying in contact with others, activity adaptations, and relocation.

Being Intentional About Contact

To combat social isolation, participants became intentional about reaching out to friends and family. One participant asked himself, "What can I do to compensate? . . . I started making at least one phone call a day. . . trying to keep in touch as one way to deal with the obstacles . . . from the COVID." Others stated, "I've had to be more aggressive or assertive in making sure that I stay in touch with friends and relatives and even people that I don't

really know that well," "The first thing I think of (in the morning) is who am I going to contact today and how am I going to do that? Because I don't want to be stranded here at home without anyone to talk to" and "I've had to work harder at social interaction."

Activity Adaptations

Activity participation was adapted. Some statements that relate to this include: "Church service is down to every other pew and five feet between people" and "We don't have communion in the way that we used to have it. We had to pick up our glasses ourselves and take into the sanctuary." One participant emphasized:

> I went and parked my car at the curb . . . in front of the church because we were doing commitment Sunday . . . they spaced out everybody. But I just stayed in the car . . and everything was on the front steps and music can somehow be heard. I got part of it, and that was really important to me.

If possible, participants socialized outdoors: "We sit out sometimes on the porch and talk." Others voiced, "we talk over the fence and that's kind of nice" and "(The restaurant) has a patio outside and just get together (with neighbors)."

Some activities pivoted to online offerings and the benefits derived from and disadvantages of using online formats such as Zoom, an online meeting platform, were identified. "Thanks to Zoom, we've been able to maintain . . . religious services or talks" and "I don't have to drive (to PD support group) . . . get out in heavy traffic and worry about having an accident or a whole other set of problems." A participant who "didn't like the idea of virtual classes" attended an online presentation by the local PD organization which emphasized the importance of staying physically active. The participant "thought, 'Oh, I really have to do that' (attend online exercise class)."

Zoom helped participants stay connected with family. "Thank goodness we figured it out . . . when (Zoom) came on the scene, things were better that I could see them (family) and talk to them." While useful, online visits were not the same as in-person contact, "We do Face Time with the kids, but it's not hugging and kissing them" and "I don't find Zoom satisfying at all for seeing my sons, really, and they don't seem to enjoy it that much either, but we talk once a week." Another participant shared that her husband was scheduled for in-patient surgery, "thank heavens for iPads and iPhones so at least we can see each other."

Online classes promoted socialization:

> Without the Zoom classes, I'd be lost. I don't know what I'd do. I'd be very, very down and out, but because of all these Zoom classes that (the organization) provides, it's really wonderful. I'm in a book club. I wouldn't have thought I'd be-- I'm in a book club. I do all these speech classes. I mean, I do everything that they put out. They put out a lot of stuff. I mean, almost every exercise they have, I do . . . it's been a lifesaver.

Access to national speakers was appreciated:

> Michael J Fox speaks to us through Zoom. We didn't do that with him, with Michael J. Fox, before the pandemic. Here's a man walking the same walk I'm walking: early diagnosis, 29 years old. Look what he's done with his foundation. He's 59 now, 30 years, and he tells me, 'Okay, here's my secret. I don't have a secret. I'm just trying to be grateful every day. I get up.' He just inspires me. I never would've gotten that without the pandemic because I probably never would've seen Michael.

Disadvantages to online classes compared to in-person were recognized. One participant related that when in-person 40 – 50 people joined in the support group; however, when meeting via Zoom only 15-20 people were online. Resistance, lack of knowledge regarding how to log on, and concerns regarding confidentiality were cited as reasons people might not attend online groups. When comparing online versus in-person classes, participants explained that, "because you don't have as much eyes on (you during the exercise class) it's easier to get hurt or not be using the correct form" and,

> You don't have anybody to just chat to (online) . . . even though you kind of have a little icebreaker in the beginning, you really don't get to talk to anybody. You get to see their faces and say, 'hello' and 'goodbye.' But you don't really get to share stories . . . I miss the interaction.

Another participant concurred and shared other Zoom challenges:

> Yes, it's physical (in-person boxing class), but it was also mental… it helped me mentally just to connect with people that I don't have to explain why I'm doing this or that. I mean, we all have Parkinson's, and we understand. When you're on those Zoom meetings, people talk. And then sometimes, you can't hear them. And then people start talking at the same time . . . it's better than nothing. But it's still not the same as having the camaraderie.

Insight regarding potential therapeutic benefits which extended beyond the boxing class itself was suggested. One participant shared the benefits related to travel and having to walk in and out of the gym.

> I had to get in my car and get up, walk, and go to and from the (gym)-- there'd be more movement involved rather than just going to turn on your computer and couple of steps in the house that way. It made me get up and get out. And there's a big difference between that and just walking a couple steps to the computer.

A participant who indulges in boxing as a sport acknowledged the lack of exercise equipment, "you don't have the bags (when boxing at home), the equipment that you usually have."

Two participants relocated to their beach homes for extended periods. "We thought it would be a better place to ride out the pandemic. So, we moved . . . I think it was in March or April, and we stayed there for several months." Another participant shared, "we're (at the beach house) for the month of December . . . the whole family's here. Yeah, that's what I mean by paradise. And my grandson comes almost every day."

Stress and Coping

Participants shared stress effects and how they coped during the pandemic. Stress caused physical responses, "you're slower . . . doing stuff," "activates my symptoms . . . brings up my sensations for Parkinson's" and "I have tingling in my body. I can't sleep." Others stated, "(my voice) might get a little worse," "stress will throw me into an off day," and causes dyskinesia and freezing. A specific example was shared, "when I'm watching

TV, I noticed when the climax comes . . . I tend to shake more." Participants also related psycho-emotional reactions to stress, "I get all anxious about being on time," "I'm pretty grouchy, it affects me emotionally," "I get depressed . . . withdraw," and "I can get kind of angry."

Coping Mechanisms

Various coping mechanisms were shared. Participants exercised, did deep breathing or guided meditation, stayed busy, took a nap, talked to their spouse, or kept on a medication schedule. No participant shared that their Parkinson medications had been changed during the pandemic. Keeping a positive attitude was important: "My attitude is so positive, I deal with the stress by just telling myself, 'okay, go away'" and "you've got to be positive, or you can be down and depressed." Similarly, others said they tried to avoid stressful situations, "I try to avoid it (stress). Try not to think about it. Try not to get involved and just walk away from it." One participant talked about the importance of not getting drawn into other people's negativity, "I want to help them (people who are depressed), but . . . I got to keep myself upbeat too because some people just bring you down like Debbie downer." Another asked herself, "can I make a difference in the situation? And if I can't, I don't worry about it." When one person is unable to avoid stress, she made sure her husband was available for support, "all he has to do is he'll just grab my hand and hold it real tight or grab my arm, sit next to me very, very closely, and just sort of takeover." Participants looked to other people for inspiration or focused on that for which they were grateful, "I look at the examples of others and try to be inspired" and "I'd . . . realize how I'm fortunate . . . all the blessings I had throughout my life and focus on that, not what I can't be doing, but what I've done and will continue to do someday."

Coping with the Pandemic

Participants coped with the pandemic by staying optimistic and informed. "You just have to take a positive look, see everything with a glass-half-full-type outlook," "I have to constantly give myself a little pep talk on a daily basis . . . and then I'm okay," and "learning as much as I can about it and what we can and can't do." One reminded himself, "this (the pandemic) is temporary."

Discussion

Participants described what it was like to live with PD during the COVID-19 pandemic. Data were categorized into three themes: (1) pandemic effects, (2) adaptations, and (3) stress and coping. The pandemic resulted in lifestyle restrictions that affected participants' health and required precautions. Most participants discussed how the pandemic restricted activity participation including church, exercise, travel, and spending time with family and friends. References to lack of social interactions and physical contact such as hugs were common. Precautions were taken to avoid exposure to the virus. Participants wore masks and gloves and minimized contact with others.

Lifestyle restrictions affected physical and mental health. Like previous findings, the pandemic affected participants' physical health (APDA, 2020; Brown et al., 2020; Prasad, 2020), and caused fatigue (Antonini et al., 2020; Prasad et al., 2020; Shalash et al., 2020). Our respondents specifically identified greater stiffness, weakness, and more frequent freezing episodes and attributed symptoms to less activity and exercise. Congruent with Shalash's report (2020), psychosocial well-being was negatively affected. Symptoms portrayed by our respondents reflect previous findings: depression (Helmich et al., 2020; Prasad et al., 2020; Shalash et al., 2020), social isolation, loneliness (Subramanian et al., 2020), fear, anxiety (Antonini et al., 2020; Prasad et al., 2020; Shalash et al., 2020), and decreased cognition (Brown et al., 2020). However, these results are in contrast with El Otmani (2021) who reported no change in depression or anxiety scores following a six-week confinement. At the time our interviews were completed, two participants were in the process of communicating depressive and anxiety symptoms to their physicians. Interestingly, when initially asked if the pandemic affected them these participants initially denied any effects. Only after responding to the interview questions did they come to realize that the pandemic had impacted their emotional health. This suggests that people might not realize the extent of stay-at-home directives, precautions, and social distancing. Upon reflection, the researchers believe that asking questions about the pandemic and allowing the participants to openly share their pandemic experiences allowed them to reflect and realize that the pandemic affected their symptoms of anxiety and depression. In support of the work of Antonini et al. (2020), participants perceived themselves at greater risk for COVID-19 and poor outcomes if the virus was contracted. Although some healthcare appointments were delayed, all but elective procedures had been completed either face-to-face or virtually. Unlike Antonini et al. (2020), none of our participants' levodopa doses had been changed since the pandemic onset.

Adaptations to usual face-to-face activities were described. Participants were intentional about connecting with friends and family and participated in activities using social distancing. Zoom was appreciated for bringing participants together with family as well as online classes and national speakers. However, limitations of online programming were recognized including the inability to socialize one-on-one during online classes, lack of touch, and camaraderie. Pre-COVID several of the participants attended Rock Steady Boxing where they used equipment such as heavy and speed bags, BOSU® balance trainers and weights, which were absent in the online environment. The use of specialized exercise equipment promotes optimal physical outcomes and its absence might explain participants' worsening PD symptoms. Confidentiality, knowledge, and resistance to online classes were cited as possible reasons for reduced online compared with face-to-face attendance. One participant appreciated online programs because the need to drive on busy highways was eliminated while another suggested that having to leave home to attend face-to-face classes had therapeutic benefits.

Stress caused physical and psycho-emotional responses as well as cognitive symptoms. Physical responses to stress specific to their PD symptoms included slow movement, tingling, dyskinesia, worsening tremors, and freezing. Anxiety, grouchiness, depression, withdrawal, and anger were psycho-emotional responses identified. Participants coped with stress in

various ways, such as exercise, meditation, talking to someone, maintaining a positive attitude, not letting things bother them, being grateful, and looking to others for inspiration. Specific to the pandemic, participants stayed informed, positive, and participated in self-talk.

Limitations

Findings should be considered in light of limitations. This was a small homogeneous sample. All were white, educated individuals, recruited from two service organizations in Texas, and unaware of their PD staging. At the same time, everyone with PD experiences different symptoms and stress responses creating heterogeneity. Given the global nature of previous literature, describing the pandemic's effect on people with PD, we expect that experiences will vary based on the duration of lockdown restrictions, cultural and contextual factors. For these reasons, the findings are not generalizable. Researcher bias is a limitation when doing phenomenology; however, investigators focused on the essential meaning of individual codes and discussed categories and themes extensively. While the literature is evolving, many of the research studies had small sample sizes limiting the science and understanding of this novel virus in the PD population.

Implications for Practice, Research, and Education

The long-term consequences of the COVID-19 pandemic on people with PD are yet to be determined. All healthcare providers should be educated regarding the physical and mental health effects of the pandemic on people with PD. Specifically, education should address how restrictions cause social isolation and lack of activity engagement which in turn worsens PD symptoms, depression and anxiety. Based on current findings, providers should assess changes in PD symptoms, explore symptoms of depression, anxiety, and cognition, and stress the importance of regular exercise to prevent worsening of PD symptoms. Coping mechanisms should be discussed and healthy alternatives explored. If patients are isolated or coping ineffectively, providers should refer them to hotlines or service organizations that offer online support and activities. Telehealth is a viable opportunity for this vulnerable population. Service providers should make every effort to train and engage people with PD in online activities. Opportunities for online socialization, outside formal classes, should be offered. Support groups and health care professionals should inform participants that stress related to the pandemic has the potential to exacerbate Parkinson's as well as anxiety, depression, and cognitive symptoms and share strategies to manage those emotional responses. Nurses should consider directly asking people with PD, "are you feeling depressed?" and "are you feeling anxious?" Further, health care providers should be alert to the potential changes in cognition brought on by the emotional response to a pandemic and be proactive in assessing as patients may not recognize the impact that it can have on their PD symptoms. Nurses and other health care professionals might recommend that patients join the Facebook group *Parkinson's International Never Give Up* to gain social support and connect with other people with PD. Appropriate referral to a mental health nurse practitioner, psychiatrist, psychologist, and PD groups is recommended.

A longitudinal study might provide insight into the pandemic's long-term effects on people with PD. Fluctuations in motor and non-motor symptoms, mental health outcomes, coping mechanisms, and medication adjustments would provide insight into care and services needed as well as the long-term effects. Lastly, because the virus is relatively new, a little over a year, more research needs to be conducted as many unknowns remain.

Conclusion

This study examined the lived experience of persons with PD during the COVID-19 pandemic. Stress exacerbates PD symptoms. The pandemic and lifestyle restrictions were perceived as stressful causing worsening PD, depression, anxiety, and cognitive symptoms. Based on the findings of this study, a holistic assessment, including physical, emotional, cognitive, and social domains should be conducted during routine visits with people with PD. Assessments must explicitly cover their emotional responses, e.g., depression and anxiety related to the pandemic. Further, cognition should also be assessed. Health care providers may consider asking the patient about their perception of their thinking during these times. Given the interplay between PD symptoms and the psychosocial impact of the pandemic, assessments require sufficient time and direct questioning to fully understand the patient's health and well-being. Inquiring about the daily activities for patients with PD will guide the plan of care for online activity, exercise, and social engagement recommendations during the pandemic.

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Appendix A

Interview Questions

- Tell me what it is like to live with Parkinson's Disease during this COVID-19 pandemic.
- How has the pandemic affected you? And, it can be in any way.
- How has the pandemic affected your health?
- What has been your biggest challenge/struggle? Please be specific.
- What have you not been able to do that you would be able to do if COVID-19 did not occur?
- Have you delayed any health care appointments due to COVID-19? If so, please elaborate.
- Parkinson's Disease is different for everyone - can you please describe how you typically react to stress/stressors? How do you deal with stress/stressors?

Probes: Tell me more... Can you elaborate? Can you be more specific? Can you give me example…?