



## Exploring the Diagnostic Journey of Individuals Living with Parkinson Disease: A Qualitative Inquiry

Emma MacPhail<sup>1</sup>, BScN, RN; Corey Hanson<sup>2</sup>, BSc, BScN, RN, & Dr. Janet L. Kuhnke,<sup>3</sup> School of Nursing, Cape Breton University, Sydney, Nova Scotia, Canada.

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<sup>2</sup> Corey Hanson an undergraduate nursing student assisted with editing and manuscript preparation.

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**Corresponding author:** Janet L. Kuhnke, Associate Professor, School of Nursing, Cape Breton University, Sydney, Nova Scotia; [janet\\_kuhnke@cbu.ca](mailto:janet_kuhnke@cbu.ca)

### Abstract

**Background:** Parkinson's Disease is a progressive neurological disorder. Criteria and guidelines have been established to improve the accuracy of diagnosis with the present accuracy of diagnosis being approximately 82%. Receiving a diagnosis of an incurable and disabling disease is a stressful life event. Accurate and timely information affects the patient's acceptance of the disease and potential treatments. The objective of the research project was to explore the experiences of patients living with PD and to give voice to the patient's perspectives related to their experiences while awaiting a diagnosis, which can take years. We explored experiences related to the individuals' physical and emotional health.

**Methods:** Ethics was sought and granted through Cape Breton University. Following informed consent, purposive and snowballing approaches were used to recruit adult participants living with PD in the community setting. Qualitative data were collected using semi-structured interviews to support five individuals to openly share their experiences. Data was typed verbatim, and a thematic analysis approach was used to compare similarities across the data.

**Results:** Participants' experiences related to their diagnostic journey were thematically analyzed and the following three themes emerged: 1) background of diagnosis, 2) healthcare support, and 3) challenges associated with the experience.

**Conclusion:** The results of this study contribute to a deeper understanding of the journey and experiences of individuals diagnosed with Parkinson's Disease. The findings emphasize the effects on an individuals' life and the importance of receiving a clinical diagnosis.

*Keywords:* Parkinson's Disease, thematic analysis, time to diagnosis; individual experience

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Parkinson's Disease (PD) is the most common neurodegenerative disease affecting approximately 10-million people worldwide (Kwok et al., 2020). The accuracy of diagnosis is 73.8% from a generalist physician and increases to 79.6 when a clinical PD expert is involved

(Rizzo et al., 2016). The incidence of PD “increases abruptly with age: several data showed prevalence varying from 1% of the general population older than 60 years to 4% of the population older than 80 years. The median age of onset is 60 years, and the mean duration of the disease from diagnosis to death is 15 years” (Rizzo et al., 2016, p. 1389). Considering Canada’s ageing population and prolonged life expectancy, the prevalence of PD is expected to double by 2040. Common and cumulative physical characteristics of PD include rigidity, tremors, bradykinesia, and gait disturbances (Goetz et al., 2015). Although the diagnosis of PD is based primarily on physical symptoms, the impact of PD is much broader, due to the struggles individuals face while adjusting emotionally, socially, and personally (Auyeung et al., 2012).

Over the past four decades, national and international guidelines and criteria have been proposed to improve and facilitate an accurate clinical diagnosis (Marsili et al., 2018). Marsili and colleagues (2018) summarized previous studies that demonstrated up to one-fourth of persons diagnosed with PD during their life have a parkinsonian syndrome secondary to alternative causes such as atypical parkinsonism, Alzheimer-type pathology, or vascular changes. Although the diagnostic accuracy has improved, researchers acknowledge there remains room for error, and that many unsolved diagnostic challenges remain. Given that it takes years to receive an accurate clinical diagnosis, this study sought to focus on the journey of individuals awaiting a diagnosis. Therefore, this qualitative research study aimed to explore the experiences of individuals living with PD and to give voice to their perspectives surrounding waiting for an accurate diagnosis. Second, this study sought to add to existing nursing knowledge by understanding the individual’s journey and the impact the disease has on their physical and emotional health.

## **Literature Review**

### **Criteria focused on Clinical Diagnosis**

Previous clinicopathological studies have identified approximately 25% of patients diagnosed with PD during their lifetime, had an alternative post-mortem diagnosis (Marsili et al., 2018). Given that the diagnosis of PD can only be obtained through neuropathology (biopsy), several criteria and guidelines have been established to improve the clinical diagnoses for individuals and their families. Parkinson’s includes clinical presentation of tremors, flexed posture, and festination; all characteristics of a new disease with an insidious onset and progressive nature called paralysis agitans (Marsili et al., 2018). Before the 1980s, there were no formal diagnostic criteria available for PD and the diagnostic accuracy was as low as 75% (Marsili et al., 2018; Rizzo et al., 2016). The United Kingdom Parkinson’s Disease Society Brain Bank proposed the first formal PD diagnostic criteria (Marsili et al., 2018). The criteria included assessing for cardinal signs: bradykinesia and at least one other sign among muscle rigidity, rest tremor, and postural instability; all secondary causes of a parkinsonian syndrome must be excluded; and three or more supportive features among unilateral onset, rest tremor, progression of the disorder, persistent asymmetry, excellent response to levodopa, severe levodopa-induced chorea, levodopa response for five years or more and clinical course of at least 10 years, should be present (Marsili et al., 2018). Considering what is now known about PD, clinicians also assess for numerous non-motor features including sleep disturbances, mood disorders, autonomic failure, sensory problems, and cognitive impairment, PD required more accurate and relevant criteria.

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In 2015, the Movement Disorder Society (MDS) proposed new clinical diagnostic criteria for PD called the MDS-PD criteria (Postuma et al., 2015). These criteria include a definition of PD, and if criteria are not met, prodromal PD or non-clinical PD could then be considered. Once a diagnosis is confirmed, the criteria then define whether this is attributable to PD when absolute exclusion criteria are absent and red flags are balanced by supportive features (Postuma et al., 2015). When these circumstances are satisfied, it is expected the diagnostic accuracy of PD will be 80%. However, this still leaves numerous patients in the cycle of not obtaining a timely diagnosis.

## **Assessment Guidelines and Management**

The diagnosis of PD is based primarily on clinical assessment findings when supported by adequate testing (Cabreira & Massano, 2019). For patients diagnosed with PD, treatment is focused on improving motor and non-motor symptoms as there are no disease-modifying pharmacological treatments available to inhibit PD progression (Armstrong & Okun 2020). Although PD is the second most common neurological disorder in America, the diagnosis can be difficult, considering a large number of the motor and non-motor symptoms are nonspecific (Radhakrishnan & Goyal, 2018). The replacement of dopamine - levodopa, is the most effective method of managing symptoms in patients with PD and the timely prescription and administration of medications are essential for long-term management (Habermann, 2016). Motor assessments of PD can be divided into clinimetric scales, assessment of balance and posture, arm and hand functioning, and gait and walking (Opara et al., 2017). After the introduction of levodopa, deep brain stimulation emerged as the second primary therapy for PD (Cabreira & Massano, 2019). Considering motor and non-motor complications are the leading cause of disability, symptoms must be identified and treated promptly (Cabreira & Massano, 2019). The treatment and management of these symptoms are important in maintaining the quality of life and ensuring positive patient outcomes. Receiving a diagnosis of an incurable and disabling disease is a stressful life event, and the timely delivery of accurate and relevant information has been shown to positively affect the individual's acceptance of the disease and treatment (Lim et al., 2017).

## **Healthcare Accessibility and Quality of Life**

As PD progresses, the quality of life for patients decreases due to motor disability and increased non-motor symptoms (Rodriguez-Violante et al., 2015). PD can negatively impact the quality of life for individuals in many aspects, particularly physical and social functioning, and loss of work income and finances. Decreased access to healthcare, whether as a result of a rural location, nursing home residence, or the presence of physical or cognitive impairment that inhibits travel, is a challenging problem for PD management (Schneider & Biglan, 2017). In many geographic areas, access to care is limited due to an insufficient number of PD specialists' neurologists, with many being concentrated in urban areas (Schneider & Biglan 2017). Schneider and Biglan (2017) report a national shortage of neurologists in America, resulting in approximately 11% of individuals living with PD lacking access to a neurologist. This is disheartening given that America has the highest number of neurologists globally. This statistic indicates, depending on the state, there is a range of 2.6-12.1 neurologists per 100,000 patients

with PD (Schneider & Biglan 2017). The shortage of neurologists is a problem that is expected to increase and will affect 19% of the American PD population by 2025.

### **Patient Experiences During Diagnostic Process**

Exploration of PD as an illness and the experiences of how patients adjust was explored by Kwok et al. (2020), who conducted 12 semi-structured interviews while focusing on understanding the illness and experiences among PD patients along with identifying reasons for psychosocial distress. Participants admitted to feeling turmoil due to the progressive loss of function and abilities, changes in role and identity, and unattended emotional needs throughout the course of their disease. One participant (male, aged 61 with mild PD) stated in his interview,

The doctor shouted at me. I remember him. I thought doctors should not only treat the disease but should also treat the patient's heart. I felt so helpless, and thus, I kept on asking those questions, and the doctor blamed me for asking too much. I would not want to know if it did not affect me. I just want to know more. (p. 5)

Due to the psychosocial impact of the disease, rehabilitation programs are implemented not only for physical symptoms but also for emotional and spiritual needs (Kwok et L., 2020). As previously discussed, prompt pharmacological intervention is essential to produce better outcomes in patients with PD. Shin and Habermann (2016) share the experiences of participants from their study evaluating how newly diagnosed patients respond to their medication regimen. They reported that 40% of PD patients acknowledged delaying their antiparkinsonian medication treatment due to difficulty accepting the disease and fear of side effects of the medication. Nurses and healthcare teams have a role to provide detailed education and monitor symptoms and medication responses in patients with PD. While initiating medication therapy, thorough assessments of patient's concerns, perceived side effects, and misconceptions regarding antiparkinsonian medications must be addressed to promote better outcomes in patients with PD (Shin & Habermann 2016).

### **Research Aim**

The study aimed to explore the experiences of patients living with PD and to give voice to the patient's perspectives related to their experiences while waiting for a diagnosis, which can take up to years. As well, we explored experiences related to the individuals' physical and emotional health.

## **Methodology**

### **Participants**

Approved by Cape Breton University's Research Ethics Board, five individuals living in the community setting of Atlantic Canada were recruited to participate in interviews. It is important to note that interviews were conducted by telephone and online during the coronavirus disease 2019 (COVID-19) pandemic. The sample size for this study was chosen due to time constraints associated with this project. Purposive and snowballing approaches were used to recruit participants. Eligibility criteria for participating in this study include (1) having a diagnosis of Parkinson's Disease, (2) being 18-years or older, and (3) speaking English.

## Data Collection

Following informed consent, purposive and snowballing approaches were used to recruit adult participants living with PD in the community setting. Data for this study were collected using a semi-structured interview with implementation and with open-ended questions. Interviews allow participants to talk about their experiences and perspectives, while capturing their language and concepts, concerning a topic such as PD (Braun & Clarke, 2013). Participants were also asked demographic questions and described the initial onset of symptoms to the formal receipt of diagnosis.

Due to the COVID-19 pandemic and social distancing recommendations by the Government of Nova Scotia (Nova Scotia, n.d.), interviews took place by video chat via Facetime (Apple, Los Altos, California, United States). Given the progression of PD increases with age and that the majority of individuals with PD receive a diagnosis at 50 years or older, phone calls were also utilized as there may be technology limitations with older adults (Fibaz et al., 2016). Virtual interviews include many advantages for participants with a neurological disease including convenience, increase accessibility and anonymity, an increased sense of empowerment and control (Braun & Clarke 2013). The audio recording was utilized to obtain a precise record of the interview via built-in iPhone recording software, Recordings were transferred to a secure USB drive and were transcribed verbatim (Braun & Clarke 2013).

## Data Analysis

A thematic analysis (TA) approach was used to compare similarities among the participants in the interviews (Braun & Clarke, 2013, 2020). To create themes among the participant's experiences, coding of each line within the transcript was completed (Braun & Clarke, 2013). TA identifies key trends of the five participants' experiences with PD which will allow us to gain a better understanding of the PD journey. Transcripts were analyzed, using TA, to identify overarching and common themes across the dataset.

## Ethical Consideration

Research ethics was sought and approved by Cape Breton University Research Ethics Board. A *Letter of Information and Informed Consent* was reviewed with each participant before the interview. Participants were reminded before the interview that they did not have to answer any questions they do not feel comfortable answering. All data files were kept on a password-protected device to protect privacy and anonymity (Braun & Clarke 2013). Data was stored in a secure location to be deleted 5 years after the conclusion of the study. Audio recordings between participants and the researcher were deleted after the conclusion of the study.

## Results

We collected rich, thick data from participants. Participants shared their journey from first experiencing neurological symptoms to receiving an accurate clinical diagnosis. Participants (n=5) ranged in age from 58 to 76, with an average age of 68.8 years. Four males and one female participated in the study. Participants reported to have lived with PD for a range of 3 to 21 years,

with an average diagnosis occurring 11.8 years ago from the time of conducting this study in April 2021.

Thematic analysis resulted in the emergence of the following themes: 1) background of diagnosis, 2) healthcare support, and 3) challenges associated with the experience. Themes and sample quotes from participants are outlined in Table 2.

**Table 1. Themes and sample quotes.**

| <b>Theme</b>            | <b>Summary</b>  | <b>Example quotes</b>  |
|-------------------------|---|--|
| Background of diagnosis | Shaking associated with PD altering day to day life                                 | <i>“One finger starting to wiggle at first... and it tapped pretty near all the time. Then it moved up my arm and my hand started wiggling... and then down my leg which started to shake. Sometimes I shook so bad... I had to get my wife to feed me my food”</i>  |
|                         | Testing primarily focused on movement and   | <i>“Mostly to do with movement... hand movements to the nose, movement with my hand turning it over ... then she had me have my shoes off and walk across the floor on my heels, then toes, then normal there and back... she also quizzed me on different things I can't remember... Parkinson's is a hard one because there is no definitive thing that they look at and say here it is”</i> |
|                         | Uncertainty in diagnosis  | <i>“Over the years it's just followed the pattern... but for some people, it doesn't... It's a little scary... You have to hope they're right”</i>   |
|                         | Participants reported that PD and Multiple Sclerosis (MS) present in family members | <i>“I have a nephew...my sister's son he's 52...he doesn't have the tremor he has a lot of muscle aches...I have a niece with Multiple Sclerosis and an uncle also has Parkinson's”</i>  |
| Healthcare support      | Neurologist accessibility   | <i>“We had no neurologists here in [in the province] ... there was one and he was booked he wasn't taking any new patients... you only get to see these guys once a year so it just depended on when you get fit in...He then went to [city] at that point...and that was too far for me to travel”</i>  |
|                         | Family physicians   | <i>“Family doctors don't know about Parkinson's...every time we receive information and books from the Parkinson's Society, we take them to our family doctor because he knew nothing about it...”</i>   |
|                         | Referrals to other healthcare professionals   | <i>“I was referred to no one...I did it all by myself...I asked my neurologist if I should be going to physiotherapy and she told me if that would make me feel better”</i>  |

|                             |  |   |
|-----------------------------|--|---|
| Challenges and difficulties | Participants reported the biggest challenge associated with loss of function | <i>“I had to get rid of everything... for the first time in my life...I didn't have a tractor”<br/>“It's the working things...he would have loved to help our girls fix up their homes...but he can't help with anything”</i> |
|                             | Medication therapy   | <i>“These drugs take a toll on you...it takes me a couple of hours every morning to get everything ready to go... it affects your movement, your slower, your joints hurt”</i>  |
|                             | COVID-19 putting a halt on support group gatherings                          | <i>“at least you got to talk to other people that had it... and some might have the same thing as you... of course, we don't have it now because of the pandemic... It's okay... but it's not the same”</i>                   |

### **Theme 1: Background of diagnosis**

Participants described the early onset of their disease and what symptoms presented initially. Participants also described the testing and diagnostic procedure they experienced along with their belief in the diagnosis. Lastly, participants described diseases that presented in their families.

#### *Shaking associated with PD altering day to day life*

All participants reported that shaking and the presence of tremors were early signs of their disease. Participants also reported experiencing symptoms including talking too low, trouble swallowing, progressive memory problems, neuropathy pain, loss of smell, and limping. One participant explains their experience with neuropathy pain by reporting *“...my neurologist told me it wasn't related to my Parkinson's... but it seems strange to me that all three people I know with Parkinson's also have this neuropathy... and it's far the worst to deal with right now”*. Another participant reported, *“...I had sharp pains in my legs... like a neuropathy pain I could barely walk”*.

#### *Testing primarily focused on movement and Uncertainty in diagnosis*

All participants reported that the testing and diagnostic process primarily focused on movement while emphasizing ambulation. Other reported assessments included hand movements to the nose, hand turning movements (i.e., pronation and supination), eliminating other possible diagnoses, and testing for reflexes. The lack of specific diagnostic testing reportedly resulted in a lengthy journey to their diagnosis and surrounding uncertainty among participants. One participant reported *“...one of the persons in our support group was misdiagnosed...they initially told her she had MS...then she went to a different neurologist.... they were ready to put her into long-term care she had to stop working.... then she went to a different neurologist, and he said you don't have MS you've got Parkinson's and they gave her the Parkinson's medication and when she came to our group she was walking again and before that she was just about bedridden.... she was up walking again, and she went back to work she was a teacher”*. Another participant reported *“...because there's not test, it still bothers me. I know it could be something*

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*worse...but is this really what I have... there are so many neurological diseases with similar symptoms...it would be nice to know definitely”.*

*Participants reported that PD and Multiple Sclerosis present in family members*

Participants discussed if PD also exists within their family. One of the participants reported having a relative with PD, two participants reported having a family member with undiagnosed tremors, and another two participants reported having a relative with MS.

## **Theme 2: Healthcare support**

Participants discussed the care and support they received from their healthcare professionals, including family physicians, neurologists, physiotherapists, and speech pathologists. Participants also discussed the accessibility of healthcare and recommendations they have for their respective healthcare systems.

### *Neurologist accessibility*

Participants reported insufficient availability of neurologists in rural locations. Three participants living in rural Atlantic Canada reported that there is currently no neurologist located within their communities. The closest neurologists are located over an hour away in more urban settings. Another 2 participants, who in a different Atlantic province, reported after having no neurologists, the province has recently gained two. One participant reported, *“I had two visits with him then he retired... and there were no other neurologists around...neurologists are in short supply”*. Another participant stated, *“I lost my doctor when he went to work for the medical society and he had 3600 patients... so...when one doctor has to look after 3600 patients there’s something wrong with our medical system”*. A similar response was reported from a third participant reporting *“One time when I went to visit my neurologist, she said oh you have a limp... as if she wasn’t aware and I told her it was you who told me I had the limp in the first place...it’s like she didn’t even have time to read my file before I came... she forgot everything about me”*.

### *Family physicians*

A lack of understanding about PD from family physicians was commonly reported among participants. When asked what the participants recommend to the healthcare system one participant stated *“...well I think family doctors should know more about Parkinson’s because they do not...really”*. Another participant reported, *“Family doctors don’t know about Parkinson’s...every time we receive information and books from the Parkinson’s society we take them to our family doctor because he knew nothing about it...”*.

### *Referrals to other healthcare professionals*

Three participants reported their neurologists had not made any referrals to aid in the management or therapy of their disease. One participant who was referred to a physiotherapist described their experience as unfortunate and said, *“we would go there every six months and she*

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*was wonderful... she had a huge knowledge of Parkinson's...it was marvelous...then budget cuts took her away...she worked through Parkinson's society and then there were budget cuts and she was gone...it was the one thing that personally dealt with the people".* Another participant who was referred to a speech pathologist also encountered an unfortunate experience as they stated *"I've been to a speech pathologist but she said she can't detect anything...most of the time when I'm talking to people on the phone they say is there something wrong with your phone can you speak up...I just tell them ill speak louder but it's not the phone...but when the speech pathologist is only two feet away from me it's pretty hard to not understand somebody...I told her myself...I can feel it in my throat I can hear it in my own ears when I'm talking my voice will give out...at this point, she said everything's okay and sent me home with some exercises and I didn't see her again..."*

### **Theme 3: Challenges and difficulties**

Participants discussed the biggest challenges they have faced throughout the course of their disease this far including loss of function and ability, medication side effects, and COVID-19. Participants included the negative emotional and physical effects when speaking about their journey.

#### *Participants reported the biggest challenge associated with loss of function*

All participants reported a physical deterioration in their health status. Participants reported that due to their disease progression, they have had to give up many hobbies, activities, and belongings including driving a car or tractor, changing their place of living, not being able to work in the woods, and not being able to complete tasks for children. One participant reported, *"my walking deteriorated fast... everybody was asking what was happening to me and everybody was noticing...last year was really tough it hurt to walk, and I had to focus on every step and I felt like I was losing everything...I didn't know what the future looked like"*.

#### *Medication therapy*

Negative side effects from Parkinson's medication including Carbidopa/levodopa have been reported from participants including stiffness in joints and muscles, nausea, insomnia, and night terrors. One participant reported, *"If I had to do it over again... I'd wait even longer because the side effects from the medication are just as worse as the symptoms of the disease..."*. Another participant reported, *"these drugs take a toll on you...it takes me a couple of hours every morning to get everything ready to go...it affects your movement, you are slower, your joints hurt"*.

#### *COVID-19 putting a halt on support group gatherings*

Four participants reported that their support groups within their communities have been affected by the pandemic COVID-19. Participants report moving from in-person to online virtual meetings which have caused difficulties for some members. One participant reported, *"...because of the pandemic we haven't been able to meet very much in the past year...we've started Zoom...before that we met once a month and then they wanted to try twice a month...a lot*

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*of them aren't computer savvy if you're thinking about the age we're talking about here".* Another participant reported, *"I reached out to the Parkinson's Society here in PEI about joining a group... but because of Covid they weren't doing anything".*

## **Discussion**

The results of this study contribute to a deeper understanding of individuals' journeys and experiences living with PD, and contribute to the nursing literature. This study is unique as it was completed with participants from Atlantic Canada. This study, though small, revealed rich information about the lives of persons living with or waiting to be diagnosed. Findings reflect the journey of living with symptomology, seeking health care support, waiting for tests and test results, and living with the diagnosis. Participants described life stress resulting from ineffective coping and uncertainty about the diagnosis. This is congruent with a study focusing on a Chinese population and setting (Kwok et al., 2020). Participants reported that most of their diagnostic assessments revolved around movement and walking tests. Literature supports these assessments, including Opara et al. (2017), identifying motor assessments of PD being divided into an assessment of balance and posture, arm and hand functioning, and gait and walking. Literature suggests that trends among individuals with PD feel disconnected from the healthcare system cause feelings of being alone and fear for the future (Kwok et al., 2020; Schneider & Biglan, 2017; Shin & Habermann, 2016). This was similar to our study, and more research is needed to understand the lived experience of persons with PD.

Kwok et al. (2020), further reported individuals with PD admitted to feeling turmoil due to the progressive loss of function and abilities, changes in role identity, and unattended emotional needs in the course of their disease. Schneider and Biglan (2017), also reported in many geographical areas, access to care is limited due to an insufficient number of specialists for PD and neurologists commonly being concentrated in urban areas. When discussing the challenges associated with their disease, participants also reported the negative side effects of medication therapy. Shin and Habermann (2016), reported in an international study, 40% of PD patients acknowledge delaying their antiparkinsonian medication treatment due to difficulty accepting the disease and fear of side effects of the medication. There are obvious trends that individuals with PD require additional support and education about their disease to achieve healthier outcomes. In this study, participants described worry from medications and related side-effects. Support groups are crucial as they offer peer support and potentially offer educative learning about medication. It is known that PD has a genetic component and can be inherited. Parkinson's Foundation (2021), reports that genetics cause about 10% to 15% of PD cases internationally. In some families, mutations in certain genes are inherited or passed down from generation to generation.

### **Study Implications**

Similar studies with persons awaiting or receiving a PD diagnosis are needed to help establish the experiences and views of patients. The lived experience of persons with PD requires further exploration. This will help to influence development of community peer support groups and clinical practice. More research is needed to understand the time waiting for a diagnosis, as in some parts of Canada this can take many months to years. Research will help to improve the care delivered to persons waiting or receiving a PD diagnosis.

## Conclusion

New findings from this study that were not identified in previous literature include symptoms of neuropathy with the disease, a lack of awareness from family physicians, and multiple sclerosis occurring in family members of PD individuals. Based on results these were all key findings among participants and require further research and implementation of new strategies. Overall, this small study emphasizes the need for further research and resources for individuals living with PD. Greater diagnostic assessments are needed to ensure an accurate diagnosis. Also, greater education is needed for patients along with proper direction and guidance to achieve healthier outcomes.

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