

## “I live a life of frustration...”

Individual with Parkinson’s disease



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**Abstract:** *Parkinson’s disease (PD), a movement disorder related to dopamine insufficiency in the brain, affects 7 to 10 million people worldwide. Research has focused on etiology and treatment, while research on how patients deal with PD is limited. This ethnographic study explored the illness experience of 14 participants living with PD. The metaphor, “Sailing the Seas in the Eye of the Storm” depicts their experience. Content themes “Daily Negotiations in the Midst of Uncertainty” (the storm) and “Reconstruction of the Self” (the traveler’s voyage) suggest aspects of holistic care for PD patients.*

**Key Words:** *chronic illness, ethnography, Parkinson’s disease, movement disorders*

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By Melinda Hermanns

# WEATHERING THE STORM:

## Living With Parkinson's Disease

**P**arkinson's disease (PD), a chronic, progressive movement disorder, affects an estimated 7 to 10 million people worldwide, 1 million of those in the United States. Sixty thousand new cases are diagnosed annually in the United States and many more cases remain undetected. The cause of PD remains unknown even though there are known risk factors associated with the disease. The primary risk factor is increasing age. PD is most frequently associated with older adulthood, affecting 1 in 100 Americans 60 years and older and 4% of Americans 80 and older. An estimated 4% diagnosed with PD are diagnosed before age 50. Early-onset (ages 21–40 years) and juvenile-onset (<21 years) PD exist, but in general, the prevalence of PD increases as people live longer. Men are affected one and half times more than women (Heyn & Stöppler, 2010; Parkinson's Disease Foundation [PDF], 2010).

PD, referred to as shaking palsy or “paralysis agitans,” was first recognized in 1817 by British physician and apothecary, James Parkinson, in “*An Essay on the Shaking Palsy*” (Parkin-

son, 1817). Interestingly, descriptions of PD symptoms date back as far as 5,000 years to an ancient Indian civilization (Heyn & Stöppler, 2010), suggesting the disease has been around for millennia.

### WHAT IS PARKINSON'S?

PD is a neurodegenerative disorder characterized by idiopathic degeneration of dopamine-producing neurons in the midbrain area known as the *substantia nigra* (PDF, 2010). Symptoms of PD result from dopamine insufficiency. Pathologically, the disease is characterized by the formation of Lewy bodies, abnormal collections of proteins in the neurons demonstrated at autopsy with histological examination of brain tissue. Diagnosis is made based on symptoms, although neuroimaging techniques also can aid diagnosis. Since the 19th century, researchers have attempted to identify one causal agent including environmental factors, stress, heredity (PD runs in families), and infection. Currently, PD is thought to be a heterogeneous disease rather than a single disorder (Jankovic, 2008).

The progression of parkinsonian symptoms may be rapid or may take 20 years or more to develop. The disease is

characterized by the four cardinal signs of resting tremor, rigidity, bradykinesia (slowed voluntary movement), and postural instability (impaired balance and coordination) (Samii, 2007). Other manifestations include dysphagia (difficulty swallowing) (Sapir, Ramig, Countryman, & Fox, 2007); difficulties with speech (Sapir et al., 2007); urinary problems or constipation (Quigley, 2007); excessive sweating and other skin-related problems (Chelimsky, 2007); small handwriting (Samii, 2007); gait disturbances (Giladi & Nieuwboer, 2007); and sleep disturbances (Comella, 2007). Symptoms typically start on one side of the body and progress to bilateral involvement (Jankovic, 2008). Freezing, a hallmark of PD, results in difficulty starting or continuing movements (Samii, 2007). Additionally, depression, anxiety, and cognitive impairment frequently occur in persons with PD (McDonald, 2007). Recent research has shown that cognitive decline and dementia in individuals with PD might be predicted by low blood levels of epidermal growth factor (EGF), an easily measured indicator (PDF, December 8, 2010). Table 1 offers early warning signs of PD that

can be useful in determining if further evaluation is needed.

Although several scales for assessing progression of PD exist (Schrag, Spottke, Quinn, & Dodel, 2009), the disease has been conceptualized for many years in a five-stage progressive model in which Stages I–V indicate relative level of disability (Hoehn & Yahr, 1967). In Stage I, the person experiences unilateral symptoms with no disability; Stage II represents progression to bilateral symptoms. In Stage III, function is still independent but symptoms progress and there is postural imbalance; in Stage IV, substantial assistance is needed but the person can still walk or stand; in Stage V the person is totally disabled (Hoehn & Yahr, 1967). There are no standard tests to diagnose PD; diagnosis is based on clinical findings and response to treatment. Interestingly, 10% to 25% of diagnoses have been found to be in error at autopsy (Jankovic, 2008).

It is important to note that Parkinson's is not a fatal disease; progression and severity of symptoms are not predictable and vary greatly from individual to individual. Unfortunately, secondary complications from the disease symptoms such as falling, choking, or pneumonia can cause death. Effective treatment and management of symptoms can lead to long and productive life after diagnosis; research has shown the life expectancy for those diagnosed with PD is comparable with those without the disease (Heyn & Stöppler, 2010).

## SYMPTOMATIC TREATMENT

Treatment for PD is symptomatic rather than curative, with the goal of increasing the amount of dopamine in the brain by (a) replacing dopamine, (b) mimicking dopamine, or (c) prolonging the effect of dopamine by inhibiting its breakdown. Levodopa has been the mainstay treatment for many years (Simuni & Hurtig, 2007). Because only a small percentage (5%–10%) of levodopa crosses the blood–brain barrier, the remaining amount is metabolized as dopamine in the body causing significant side effects (dyskinesias, stiff-

ness, nausea). Drugs such as carbidopa (Lodosyn) or benserazide (Madopar, Prolopar; approved in the UK and Canada) are given to inhibit peripheral metabolism of levodopa. Combination preparations of levodopa and carbidopa (Sinemet, Atamet) often are used.

Unfortunately, the side effects of levodopa increase and effectiveness of the drug decreases over time. Therefore, instead of levodopa, early treatment of PD symptoms often involves the use of dopamine agonists that mimic dopamine by activating dopamine receptors, and monoamine oxidase type B (MAO-B) inhibitors that reduce the breakdown of dopamine. Side effects of these include orthostatic hypotension, dizziness, nausea, and constipation (Jankovic, 2008).

Estimated annual medication costs for a person with PD in the United States averages \$2,500. Adjunctive treatments such as rest, routine exercise, physical therapy, occupational therapy, and speech therapy can be beneficial in symptom management (National Parkinson Foundation, 2010; PDF, 2010).

Although there have been a number of pharmacological advancements for PD, the reality is that medications work for a limited time, often requiring increasingly higher doses or more medications to control symptoms. Surgical treatments such as deep brain stimulation (DBS), in which a neurostimulator or “brain pacemaker” is inserted into the brain, are available but reserved for those who no longer respond to medication or for those who experience intolerable medication side effects (Malhado–Chang, Alterman, & Tagliati, 2007). Individuals who have had DBS continue to take medications and must have routine adjustments to the neurostimulator for symptom control. Overarching goals of treatment are aimed at alleviating symptoms and maintaining independent function.

Controversial treatments such as stem cell therapy are thought to offer hope for the future of PD treatment. However, in addition to the ethical problem of using embryonic stem cells, which can destroy potential life, many scientific hurdles to transplants remain. Immune mismatch, potentially

fatal graft-versus-host disease, and the risk that transplanted stem cells could form tumors and become cancerous if cell division continues uncontrollably are concerns for stem cell therapy. In laboratory studies, embryonic and adult stem cells have been transformed into cells that produce dopamine, and transplanted stem cells helped restore dopamine production in experiments in primates. However, it is unlikely that specific treatments will be available for many years (Consumer Reports, 2005; Sullivan & Schoonover–Shoffner, 2007).

## THE ILLNESS EXPERIENCE

The bulk of PD research has focused on the biomedical model seeking to understand etiology and treatment, while research on how patients deal with PD daily is limited. Specifically, there is little understanding of the illness experience and impact of the disease on persons with PD.

An ethnographic study was used to elucidate understanding of the illness experience of persons with PD. Ethnography involves the study and description of human cultures and is based on fieldwork that includes participant observation and in-depth interviews (Denzin & Lincoln, 2005). The goal of ethnography is providing a “thick description” and rich understanding of the “lived experience” of participants (Dewalt & Dewalt, 2002). This study examined a group of individuals with the common experience of living with PD in an attempt to see their illness experience through their eyes and understand what is like to live with PD on a day-to-day basis. Such information assists healthcare professionals supporting patients with PD.

Two support groups were purposively selected for fieldwork: the early-onset PD group for individuals diagnosed under the age of 60 and the Parkinsonians of East Texas for individuals over the age of 60 when diagnosed. The sample included 14 nonhospitalized persons with PD; 7 females and 7 males ranging in age from 38 to 82 years (mean age 68.4 years). The staging of the participants with PD was as follows: Stage I ( $n = 2$ ),

Stage II ( $n = 2$ ), Stage III ( $n = 3$ ), Stage IV ( $n = 6$ ), and Stage V ( $n = 1$ ).

Letters of support were obtained from the support groups allowing the researcher access to individuals who attended group meetings. Each participant was provided with written information about the study. Confidentiality was assured and written informed consent obtained. Institutional review board approval was obtained from university committees.

Participant interviews were tape-recorded and transcribed; transcripts were verified to ensure accuracy. An iterative process continued throughout analysis to ensure data were appropriately represented. Data were collected until saturation and redundancy occurred; saturation was determined when rich, thick descriptions of categories themes were established. A detailed report of research methods and data analysis can be found in Stanley-Hermanns and Engebretson (2010), "Sailing stormy seas: The illness experience of persons with Parkinson's disease."

### SAILING STORMY SEAS

The question, "What does it mean to you to have PD?" attempted to illuminate the existential meaning of what it means to live with this disease. Participants referred to the devastation and debilitation of PD with comments such as:

*"It's bad because you can't do as much, and you can't do the things that you used to..."*

*"Devastating... I just simply wasn't going to have Parkinson's. Then the symptoms got worse... my world has gotten so small. I can get out of the house maybe once a month and not realize it [experience worsening symptoms]. I stay in my room more."*

*"It's debilitating because it doesn't [sic] allow you to do the things that you have been used to doing."*

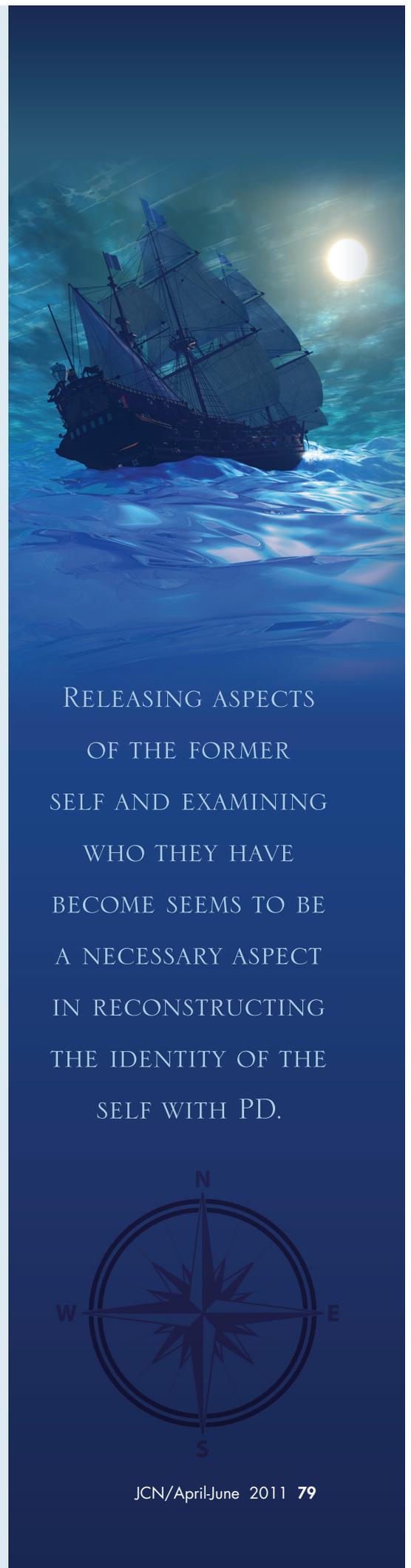
*"Very frustrating... I can't do things with my wife. I don't have a problem accepting it; it is just the sheer frustration that you can't do anything. I live a life of frustration."*

The metaphor, "Sailing the Seas in the Eye of the Storm" depicts the ill-

ness experience of the seven men and seven women facing the storm called PD. This dramatic phrase reflects a sense of adventure and unpredictability, and gives a glimpse into what it is like to live daily with PD. One participant summarized the experience as, "It's rough." The first aspect of this metaphor is the storm itself, and the second is the traveler's voyage. These participants have embarked on a journey on stormy seas and can never return to where they were. Two content themes that emerged were "Daily Negotiations in the Midst of Uncertainty" (the storm) and "Reconstruction of the Self" (the traveler's voyage).

The theme "Daily Negotiations in the Midst of Uncertainty" came to light when all 14 participants reflected on day-to-day activities but were unable to describe a "typical" day. The unpredictable nature of PD requires the person to deal with uncertainty on a daily basis, much like a sailor sailing treacherous seas. It became increasingly evident in all 14 participant responses that PD determines what the person will do on any given day. All shared personal accounts of their internal and external day-to-day checks. The unpredictability of day-to-day management, coupled with the uncertain progression of the disease, was identified as one of the primary reasons why the participants in this study could not describe a typical day; there is no typical day in PD. Each participant was forced to find new ways of negotiating daily living as well as construct meaning of their illness experience and perception of self, knowing their illness will never go away. The need to negotiate activities minute to minute became a constant reminder of the uncertainties of PD, and that taken-for-granted aspects of day-to-day management would never be the same. One of the younger participants expressed the process of daily negotiation and uncertainty of PD:

*"So I live with Parkinson's on a daily basis... I have to adjust my times... do it [daily activities] slowly or do it differently... I don't know how fast my disease is going to progress. So*



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*the uncertainty of where I will be at what stage I will be in my disease... I don't know, see, the uncertainty...*

The theme "Reconstruction of the Self" describes the traveler's voyage. Participants continued to reflect on their voyage of PD and its impact on the self in an attempt to redefine their individual sense of personhood. This dynamic process involved a continual effort of examining their former self, then attaching meaning to their revised self-perceptions of the self with PD. One person emphatically stated:

*"I realized that I would never be the same... I could never go back to being the old me, and I am okay with that, now. It took me some time to get to the point that I was okay with it..."*

Each participant processed and integrated knowledge about PD to develop response strategies consistent with their personal values and style. Although PD was not in their original life plans, participants modified their plans to accommodate their disease. All participants expressed plans of traveling, spending time with their significant other, and enjoying their retirement years, yet the new reality of their golden years is PD. Participants stated things like:

*"We had plans of retiring and traveling. I never dreamed PD would be my retirement."*

*"I couldn't wait to have grandchildren and now the time is here, I can't even hold them or play with them."*

All 14 participants were forced to deal with the pain and suffering of the physical, psychological, and social ramifications of living with a chronic, progressive disease. The pain and suffering of this unknown voyage illuminates the realization that these individuals made in living with the transitioning self. Their life requires minute-to-minute negotiations of daily activities in the midst of uncertainty. Their focus was on the voyage, living with PD, rather than the final destination, death. In their quest to discover a

deeper meaning of self, they redefined self, drawing on strengths they didn't know or remember they had. Through inner strength and determination they found a way to fit PD into the overall schema of a meaningful life. Some relied on their faith, turning to a Higher Power, God, while others turned their imposed imprisonment into their own good, reaching a sense of resolution with self and PD.

## SPIRITUAL JOURNEY

"We live by faith, not by sight" (2 Corinthians 5:7) resonated as participants shared their spiritual journey. To weather the storm of PD, participants had to release aspects of self, which included control over their body and their dreams, former expectations, and future plans. One way they did this was through surrendering to a Higher Power, which facilitated their release/reconstruction of the self. This release expressed by the participants may be metaphorically compared to the feeling of safety in spite of the storm. Spirituality was one factor that facilitated the release. Releasing aspects of the former self and examining who they have become seems to be a necessary aspect in reconstructing the identity of the self with PD. As a result of the PD diagnosis, the 14 participants were forced to make meaning of their present self, the self with PD. Many admitted this was not an easy task; rather it required patience, perseverance, and a willingness to embrace their present self and the limitations associated with PD. One participant eventually determined she was not in control of anything and stated she was forced to "let God be God in my life and depend on him." Even though she had been a Christian since age 10, this deeper dependence on God made a considerable impact on her everyday life.

Two Parkinson's support groups were attended, in addition to the individual participant interviews. Participant comments at the support group further attested to their spiritual faith, such as:

*"I surrendered to him [God]; without him I would have just given*

*up. I know I would not have been able to accept that I can no longer work like I always had done in the past.”*

It is important to make a distinction between surrendering to God and surrendering to the disease. Surrendering to the disease means giving up, whereas surrendering to God implies hope.

All participants indicated they had a strong faith in God. For most, their active expression of their spiritual faith in God was identified as the process by which they came to terms with PD. It was as if the participants recognized their physical, psychological, and spiritual limitations and allowed God to take control of the helm. More specifically, their inner strength, perseverance, and strong faith were seen as an impetus toward acknowledging that they will never be the persons they were, persons without PD. Although a majority of the participants expressed a closeness to God as a result of their illness ( $n = 12$ ), two stated there was no change as they felt their spiritual faith remained strong despite the diagnosis. In their quest to discover a deeper meaning of self, many relied on their spiritual faith:

*“But like I tell them, maybe God knew, and so I don’t ask why, I just say here I am, Lord, you know why. I am so thankful that even if it took this, even if it took this to get my life in order and my relationship, you know, recommitting my life to God, then I am thankful for that because I know what I have to look forward to after death.”*

*“So number one is to serve God. My relationship with God is really what gives me the daily strength.”*

*“My relationship with God has improved. You count your blessings.”*

*“It just made me a giver, I guess. It has made me a stronger person.”*

*“I am closer to God, I think than I ever have been. God has never left me. I was always the one that turned around on him. He has always been there. It made me realize that I needed him more in my life....Now [I] really stop and think about what is important before [I] start the day.”*

*“I just let God take over. I said, ‘Here I am God, you know better than me’.”*

Once the PD diagnosis was established, participants indicated there was no chance of resuming life before the disease. In the model, “Sailing the Sea in the Eye of the Storm,” abandoning ship through total withdrawal or even suicide was the option for all participants, but they weathered the storm and persevered. One participant considered suicide as she witnessed firsthand her deterioration and remembered the demise of her mother, sister, and aunt from PD. But she changed her mind when she considered the effect suicide would have on her family. One middle-aged gentleman in the early-onset PD group shared:

*“I’ve often thought about options of ending it all, but I am stronger than my disease. I want to live.”*

## RECONSTRUCTING SELF

Participants relayed that PD directly challenged life as they knew it and, in essence, all that their lives had stood for. The complex paradox and ongoing tension between preserving self while releasing aspects of the former self in reconstructing the new self with PD can be metaphorically linked to “Sailing the Sea.” The process of reconstructing the self with PD requires participants to embark on a solo journey on stormy seas where the seas are unpredictable, fluctuating, and complicated with no chart or clear course. This voyage involves reconstructing a new self with PD, a major theme for constructing their illness experience. Note this process was not linear—rather it was a dynamic process that enabled participants to examine who they were and what was to come. This process involved a continual effort of examining their former self, then attaching meaning to their revised self-perceptions of the person with PD.

**TABLE 1.**  
10 Early Warning Signs of Parkinson’s Disease

Consider Parkinson’s if these symptoms occur without any other known etiology:

1	Tremor, twitching, or shaking in a limb, finger, thumb, hand, chin, or lip
2	Handwriting suddenly smaller than in the past; words crowded on the page
3	Loss of smell, especially of certain foods (bananas, licorice, dill pickles)
4	Difficulty sleeping, sudden movements during deep sleep (thrashing, kicking, falling out of bed)
5	Trouble moving or walking; stiffness not relieved by movement (arms don’t swing, feet “stick to the floor”)
6	Constipation
7	A change in voice, speaking more softly or in low tones, sounding hoarse
8	Masking; a serious, depressed, mad-looking face or blank stare when not in a bad mood, rarely blinks eyes
9	Regular dizziness or fainting, orthostatic hypotension
10	Stooping, leaning, or slouching upon standing

Source: National Parkinson’s Foundation (2010).



## Web Resources

- Parkinson's Disease Foundation—<http://www.pdf.org/>
- National Parkinson Foundation—<http://www.parkinson.org/>
- Movement Disorder Society—<http://www.movementdisorders.org/>
- WE MOVE—<http://www.wemove.org/>
- WobblyWilliams.com—<http://www.wobblywilliams.com/>

PD affects a person biologically, psychologically, and socially. Although technically a disease of the brain, PD is a multisystem disabling disease. The awareness that their ship was not going to return was a reality, despite holding a compass and a reconstructed map to their final destination. Many participants were able to say “bon voyage” to their former self, pull anchor, and “cast off” to the treacherous sea, leaving this researcher to share their stories in hopes of continuing their legacy.

A finding not previously found in the PD literature, and unique in this study, was the paradoxical balancing in preserving and maintaining self while simultaneously releasing aspects of the former self to reconstruct a new self with PD. This study illuminated the struggle of dealing with the uncertainties and fluctuations of PD, while reconstructing perceptions of a new self. One participant stated,

*“I’m still the person I was, but I have to be realistic; I look different, I walk differently, and [I] shake a bit, but it’s me...”*

### STUDY IMPLICATIONS

For healthcare providers, we must look beyond the disease and see the person. We can assist when we acknowledge the person's past and recognize that clients may benefit from talking about their past (the self before PD) and how PD has affected them and they are coping in the present (the self with PD). Such holistic assessment should be incorporated into care for individuals with PD. Educational approaches need to be developed that enable nurses to provide reality-based care for patients with PD and other

chronic illnesses, and to strongly emphasize psychosocial and cultural impact when caring for persons with PD.

The significance of spirituality and reliance on faith to participants in this study suggests the importance of assessing and supporting spirituality for individuals with PD. Supporting patients in their spiritual journey would appear to be a key intervention when working with PD clients. Surrender to a Higher Power and trust in God were vital factors in participants' discovering and accepting a new self and finding a sense of safety and security in the storm of PD. For Christians, the many allusions in Scripture to God stilling the storm (i.e., Psalm 107:28-29; Matthew 8:23-27) and being a refuge in a storm (i.e., Isaiah 25:4-5) could be helpful and comforting.

This study represents the first step in a program of research intended to improve the quality of care provided to patients with PD. A long-term goal is to better understand the illness experience of persons with PD and to develop nursing interventions to improve nursing practice. Future research is needed to further examine the illness experience, including with individuals who do not express faith in God to explore the significance of spirituality in their illness journey, as well as the structural process of reconstructing the self. More qualitative studies examining the illness experience, uncovering additional complexities from the perspective of those with PD, and noting healthcare responses and testing interventions are needed. Such research could support the development of a mid-range nursing theory to deal with issues and uncertainties of daily living with PD.

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