



## Symptom progression in advanced Parkinson's disease: Dyadic perspectives



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### ABSTRACT

This qualitative descriptive study investigated the self-reported symptoms of people with advanced Parkinson's disease. Fifteen dyads (person with Parkinson's and family caregiver) participated in two semi-structured interviews over a six-month time period; content analysis was used to explore the progression and new onset of symptoms. Reported symptoms in descending order included gait deterioration, falls, speech impairment, cognitive decline, functional decline, gastrointestinal and genitourinary changes, and swallowing impairment. The presence of multiple, compounding symptoms present challenges for maintaining safety in the home, highlighting the need for in-home services to assist with symptom management. Change in self-reported symptom experience was not significantly different after a six-month time frame. Symptom progression in advanced Parkinson's disease may take longer than six months to appreciatively manifest. Therefore, future research should explore the progression of advanced Parkinson's disease longitudinally over a period of time that exceeds six months.

### 1. Introduction

Advanced Parkinson's disease (PD) as defined per the Hoehn & Yahr disability scale (Hoehn & Yahr, 1967) is characterized by physical dependence (stage 4) and/or confinement to a wheelchair or bed (stage 5) (Goetz et al., 2004). Documented symptoms of advanced PD include worsening imbalance and ambulatory dysfunction, altered cognition and/or dementia, and swallowing impairment (Bunting-Perry, 2006; Gershanik, 2010; Liberman & McCall, 2003). Most people who have PD live at home and require increasing amount of care as the disease progresses (Habermann & Shin, 2016). Although PD is not a terminal diagnosis, complications from PD can contribute to mortality (Bunting-Perry, 2006; Liberman & McCall, 2003).

The trajectory of PD is variable and individual disease progression can be uncertain (Bunting-Perry, 2006). Research often addresses the PD population broadly, capturing a range of experience across the Hoehn & Yahr disability scale. This study is specific to people with stages of 4 or 5 on the Hoehn & Yahr disability scale, presenting an in-depth exploration of the symptoms of people with advanced PD. Prior nursing research about PD primarily consists of studies assessing caregiving within families; symptom management and medication

adherence, quality of life, and end-of-life (Shin & Habermann, 2016). Preexisting studies that measure quality of life using quantitative measures such as the Parkinson's Disease Questionnaire-39 items (PDQ-39) numerically capture presence, frequency, and severity of discrete symptoms (Neff, Wang, & Martel, 2018; Peto, Jenkinson, & Fitzpatrick, 1998). Yet, there is limited prior research that qualitatively assesses troublesome symptoms from the perspectives of people with advanced PD and their family caregivers (Habermann & Shin, 2016). The purpose of this study was to investigate the dyadic-reported experiences of people with advanced PD and their family caregivers, exploring the progression and new onset of symptoms. Secondly, the study sought to determine the significance of self-reported disease progression after a six-month period. A six-month timeframe was selected due to the advanced stage of the PD participants and to ensure participants were likely to have not been institutionalized or have died.

### 2. Methods

This study was a secondary analysis of existing qualitative data obtained during a mixed-methods study (Habermann, Shin, & Shearer, 2019). This study utilized a qualitative descriptive design with a

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content analysis approach to coding, allowing for both the qualitative and quantitative analysis of data (Vaismoradi, Turunen, & Bondas, 2013). Numeric quantification of qualitative data provides ready visualization of main ideas within the dataset (Sandelowski, 2001), with interpretation remaining close to the narrative (Sandelowski, 2010).

### 2.1. Participants and setting

Potential study participants were identified through their affiliation with PD-oriented support groups and clinics in the Mid-Atlantic region. Inclusion criteria were as follows: (a) a person with advanced PD who was entirely dependent upon the use of assistive devices for ambulation (Hoehn & Yahr's stage 4 and 5); (b) a person with PD had sufficient cognitive capacity for meaningful participation; (c) a person with PD who has a family caregiver; and (d) a dyad agreed to participate in two data collection sessions spaced six months apart. Exclusion criteria for the dyad included: (a) either member being on prescribed memory enhancing medications or (b) a history of psychiatric illness. Potential participants contacted the research team via phone and a researcher described the study in-depth. Dyads who expressed a willingness to participate were scheduled for consent and data collection. Interviews were either scheduled in their home or in a location of their choice. At the prearranged date and time, written informed consent was obtained from each participant prior to the Time 1 interview.

### 2.2. Interview

Institutional Review Board approval for the mixed methods study was granted by the authors' affiliate institution prior to data collection. Two semi-structured approximately 30-min qualitative interviews were conducted with each dyad by an experienced qualitative researcher and a trained research assistant between July 1, 2014 and October 20, 2015. Time 1 Joint Interview questions include: (a) Describe how your Parkinson's disease has changed over the last two years; (b) As a family member, what have you noticed in the last two years?; and (c) What do you think may be new or worsening problems in the next year or so? Time 2 Joint Interview questions include: (a) Describe how your Parkinson's disease has changed in the last six months; (b) As a family member, what have you noticed in the last six months?; and (c) What do you think may be new or worsening problems in the next year or so? Interviews were spaced six months apart, audio-recorded, and transcribed verbatim via a professional transcription service. Transcription accuracy was confirmed by a research assistant.

### 2.3. Data analysis

Researchers independently coded Time 1 interview data prior to meeting to discuss emerging themes. Time 1 data were re-coded per its affiliation with the identified themes with thematic amendments made when necessitated by the emerging data. After inter-coder agreement was established among coders for Time 1 data, Time 2 data were coded per its association with the identified themes. Special notation was made when participants identified a specific symptom as the most troublesome for them. Charts were constructed to quantify and compare categorical occurrence within the two data sets. Most troublesome symptoms were also quantified and compared. Reliability was strengthened by having multiple researchers code the interview data. Inter-coder agreement was reached for the final list of symptoms that were reported by at least one third of the dyads ( $n = 5$ ).

## 3. Findings

Fifteen dyads ( $N = 30$ ) participated, completing two interviews for this study (Table 1). The mean age for participants with PD and family caregivers was 75.3 years old ( $SD = 9.81$ ) and 68.9 years old ( $SD = 11.99$ ), respectively. Eleven participants with PD were males.

**Table 1**  
Participant demographics ( $N = 30$ ).

Characteristic	Individuals with Parkinson's Disease ( $n = 15$ )	Caregivers ( $n = 15$ )
	n(%)	n(%)
Gender		
Male	11 (73.3)	5 (33.3)
Female	4 (26.7)	10 (66.7)
Race		
Caucasian	14 (93.3)	14 (93.3)
African American	1 (6.7)	1 (6.7)
Employment		
Currently employed	0 (0%)	2 (13.3%)
Retired due to disability	7 (46.7%)	1 (7.1%)
Retired due to caregiving	0 (0%)	4 (28.6%)
Annual household income (\$)		
10,000–20,000	1 (7.7%)	
20,000–30,000	1 (7.7%)	
30,000–40,000	0	
50,000–60,000	1 (7.7%)	
60,000 +	10 (76.9%)	
No answer	2 (13.3%)	

The mean years of education of participants with PD and their caregivers was 15.8 years ( $SD = 3.32$ ) and 15.2 years ( $SD = 2.59$ ), respectively. The mean years of living together was 41.4 years ( $SD = 15.47$ ). The mean years of living with PD was 9.7 years ( $SD = 4.59$ ). The mean years of using assistive devices was 5.9 years ( $SD = 4.54$ ). Two participants with PD were homebound and one participant was chair-bound.

### 3.1. Changes and symptoms reported in the interviews

During the first interview, dyads reported the following changes within the last two years: gait deterioration, falls, speech impairment, cognitive decline, functional decline; gastrointestinal and genitourinary changes, and swallowing impairment (Table 2). Six of seven symptoms were physical changes with the exception of cognitive decline. After six months, the dyads continued to support these seven symptoms.

#### 3.1.1. Gait deterioration

Gait deterioration was revealed to be both the most frequent ( $n = 15$ ) and troublesome ( $n = 8$ ) symptom for study participants. Symptoms manifested as scuffing of the feet, stiffness with subsequent pain, inability to ambulate unassisted, slowed movements, and freezing. Participants shared that Parkinson's associated fatigue can be debilitating, diminishing their independence. Participants described how routine tasks take significantly longer to complete and how worsening imbalance compromises the ability to stand and ambulate. An 80-year-old female family caregiver (#12) describes:

It's mostly mobility that's changed in the last two years, a lack of it and balance, standing...and the balance and the ability to stand up and transfer. The movement, he's more rigid, which is what makes it so hard to transfer because when you have to go this way he has to help and he's having more and more trouble doing that.

Ambulation is further compromised by freezing, the inability to propel one's feet forward. A 66-year-old female participant (#6) explains, "...sticky feet...when I go to get up and turn my feet, they sort of stick and they won't go forward... sticky feet and falling is the biggest thing in the last two years."

#### 3.1.2. Falls

A critical consequence of gait disturbance is increased vulnerability to falling, the second most often reported symptom of advanced PD ( $n = 14$ ). Three participants described it as their most troublesome symptom. Fear of falling was pervasive among our study population,

**Table 2**  
Thematic ranking time 1 and time 2 data from dyads (N = 15).

Rank	Time 1		Time 2	
	Symptom category	Number of dyads reporting symptom	Symptom category	Number of dyads reporting symptom
1	Gait deterioration	15	Gait deterioration	14
2	Falls	14	Functional decline	11
3	Speech impairment	13	Speech impairment	11
4	Cognitive decline	12	Cognitive decline	8
5	Functional decline	11	GI and GU changes	7
6	GI and GU changes	7	Falls	6
7	Swallowing impairment	5	Swallowing impairment	5

Note: GI = gastrointestinal; GU = genitourinary.

impacting the peace of mind and freedom of both individuals with advanced PD and their caregivers. Near-constant monitoring is often necessary for fall prevention. A 73-year-old male family caregiver (#6) explains:

It's not like a slippery thing or anything like that. It's turning most of the time, and I stay after her about trying to carry stuff. You look, and she'll have her pocketbook. When she fell, that was just before we came over here, she fell in the kitchen.

For some participants, falling occurred frequently; a 66-year-old female participant (#6) relayed "I have fallen twice already today." A 75-year-old male participant (#14) fell less often but only after "go [ing] to extraordinary lengths to avoid falling." Fall-avoidance behaviors have become interwoven throughout participants' daily routines. A 72-year-old female family caregiver (#8) explains:

His balance and his weight on his feet is not good. The big issue is you really essentially have to get him into the shower and sit him down with his shoes and socks on and then take them off. Before you get him back out of the shower you have to put the shoes and socks back on.

### 3.1.3. Speech impairment

Thirteen dyads reported speech impairment. One third of participants ( $n = 5$ ) stated that speech impairment was the symptom that caused them the greatest distress. Participants describe diminishing voice quality characterized by softening, mumbling, and inconsistent tone. A 72-year-old female family caregiver (#8) relates:

Sometimes his voice is very soft...but he mumbles sometimes you know. Sometimes he's, when he's first getting up in the morning or something, and he hasn't had his meds yet, he's mumbling, or even at night when he's tired, and it's like, I have to say you have to speak up. I don't understand what you're saying.

Speech impairment lead to one participant's retirement. A 76-year-old male participant (#11) explains, "My voice has definitely changed, and this is what bothered me because I was in sales for 27 years, and I traveled all over the United States... my voice is a determining factor for me retiring."

### 3.1.4. Cognitive decline

Impairments in memory and judgment are the fourth most commonly reported symptoms among our study participants ( $n = 12$ ). Two participants stated that memory loss was their most troublesome symptom. Cognitive decline exacerbates speech impairment by contributing to impaired word retrieval. A 79-year-old female participant (#9) explains:

I can't remember. If I want to say something or talk about something I may have it in my head, but I can't get it out. I don't talk very much now. I let other people talk and I just listen, and I don't remember.

Cognitive decline also contributes to impulsivity, and/or over-estimation of ability, increasing risk for falls. An 80-year-old female family

caregiver (#12) exemplifies:

He does not feel, he doesn't sometimes believe he can't walk and he tries to get up. So I do, we do have to have someone present all the time, cannot leave him alone because he will believe he can walk and try to get up.

### 3.1.5. Functional decline

Characterized by diminished ability to complete activities of daily living (ADLs) and psychomotor difficulty while eating, functional decline is the fifth most often reported symptom category by our study participants ( $n = 11$ ). A 79-year-old female participant (#9) describes needing assistance to complete ADLs:

We have a nurses' aide who helps us...I brush my teeth myself but she's there to help me. As far as showering I'm able to sit down on a shower chair in the bathroom...and take care of myself. She helps dry me. She gets me dressed. She helps make lunch.

Meanwhile, a 76-year-old male participant (#11) illustrates his experience with psychomotor difficulty while eating:

I eat very quickly...but I'm doing that very clumsily. In other words, when I come over fork to my mouth, either I don't open my mouth wide enough or I don't take the food off the fork as I should be doing...It has been changing, That's one thing I'm concerned about.

### 3.1.6. Gastrointestinal and genitourinary changes

Gastrointestinal and genitourinary changes is the sixth most commonly reported symptom among study dyads ( $n = 7$ ); symptoms include gastrointestinal and genitourinary dysfunction characterized by constipation, incontinence, urinary tract infection (UTI), and hesitancy. A 74-year-old female participant (#4) states "Constipation. I have terrible constipation but I'm okay as long as I eat the fruit..." A 69-year-old female family caregiver (#1) describes, "...he has been getting a lot of UTI's...we have to watch that and make sure he gets water and changed and all kind of things like that..." None of the participants described gastrointestinal and genitourinary changes as their most troublesome symptom.

### 3.1.7. Swallowing impairment

Swallowing impairment, the seventh, and final categorical symptom ( $n = 5$ ) is characterized by drooling, prolonged mastication, and choking. Only one participant described swallowing impairment as their most troublesome symptom. A 58-year-old male participant (#2) states, "I drool constantly, and I didn't use[d] to drool." A 66-year-old male family caregiver (#2) continues, "...They chew, and they chew and they chew until two hours later they're still chewing. An 83-year-old-male participant (#8) states that "It's hard to swallow." A 72-year-old female family caregiver (#8) explains:

He does choke, on water. He will not drink the water...meats and other things I have to grind up...and he is avoiding breads, because he says it gets stuck in his throat, even though we use things, I use honey. I use gravies, I use soups. I use broths.

**Table 3**  
Dyads' expectations for new or worsening symptoms in the coming year (N = 15).

Dyad	Time 1	Time 2
1	Decreased mobility, decreased independence	Decreased mobility, speech impairment
2	Decreased mobility, cognitive decline	Speech impairment, cognitive decline
3	Functional decline	
4	GI/GU complications, cognitive decline	
5	Decreased mobility, cognitive decline	Increased fatigue
6	Decreased mobility	Falls, decreased independence
7	Decreased mobility	Decreased mobility, fatigue, weakness
8	Swallowing impairment	
9	Decreased independence	Decreased mobility, weakness
10	Decreased mobility, gait deterioration, speech impairment	Decreased mobility, gait deterioration, falls
11	Decreased mobility, gait deterioration, decreased coordination	Decreased mobility, gait deterioration, falls, speech impairment
12	Decreased mobility, cognitive decline, sleep disturbance	Decreased mobility, swallowing impairment
13	Functional decline, decreased independence	
14	Decreased mobility, functional decline, falls	Functional decline, depression
15		Gait deterioration, functional decline, decreased coordination, falls

Note: GI = gastrointestinal; GU = genitourinary.

### 3.2. Expectations for new or worsening problems in the coming year

During both Time 1 and Time 2 interviews, dyads were asked about their expectations for new or worsening problems in the coming year (Table 3). At Time 1, dyads most often spoke of concerns about decreased mobility ( $n = 9$ ), followed by cognitive decline ( $n = 4$ ), and decreased independence ( $n = 3$ ). One dyad did not identify new or worsening symptoms at Time 1. At Time 2, dyads continued to speak most often about concerns for decreased mobility ( $n = 6$ ), while also endorsing expectation for falls ( $n = 4$ ), and impaired speech ( $n = 3$ ). Four dyads did not identify new or worsening symptoms at Time 2.

## 4. Discussion

The findings of this study highlight the complex and interactive nature of advanced PD symptomatology (Bunting-Perry, 2006; Muzerengi, Herd, Rick, & Clarke, 2016). Several physical symptoms reported in the study support previous findings of increased caregiving needs in the advanced PD population (Hand, Oates, Gray, & Walker, 2018). It should be noted that interviews were done as a dyad with both participants with advanced PD and their family members. They answered questions together and probes were used by the interviewers to validate agreement. Dyads agreed on most symptoms reported such as gait deterioration, falls and cognitive decline. However, caregivers more often noticed functional decline and speech impairment than did participants with advanced PD. Although many of these symptoms could be experienced among the general population of older adults, gait deterioration, speech impairment, and swallowing impairment are more unique to those with advanced PD, and warrant increased consideration due to their potential contributions to hospitalization/institutionalization and increased morbidity and/or mortality (Beydoun et al., 2017; Beyer, Herlofson, Arslan, & Larsen, 2001; Muzerengi et al., 2016; Nóbrega, Rodrigues, & Melo, 2008; Plowman-Prine et al., 2009).

Gait deterioration directly contributes to increased fall risk (Beydoun et al., 2017; Muzerengi et al., 2016). People with PD are hospitalized more often due to fall-related injury than are older adults at large (Vossius, Nilsen, & Larsen, 2010). Falls are a predominant cause of injury-related hospitalization (Alamgir, Muazzam, & Nasrullah, 2012), and are the leading cause of fatal injury among older adults in the U.S. (CDC, 2016). In advanced PD, speech is inhibited both by the slowing and stiffening of vocal and respiratory muscles (Lieberman & McCall, 2003) and by memory lapse. Swallowing impairment presents significant risk for choking and aspiration pneumonia (Habermann & Shin, 2016). Thus, better symptom management in advanced PD could prevent potential hospitalization and institutionalization (Hakkarainen,

Arabi, Willis, Davison, & Flum, 2016; Muzerengi et al., 2016).

Most people with advanced PD are cared for at home by at least one family caregiver (Habermann & Shin, 2016; Shin & Habermann, 2016). Although many people with PD and their spouses prefer to remain in their homes (Habermann & Shin, 2016), the progressive nature of PD increases the likelihood that family caregivers could become overwhelmed while providing care in a home setting (Hand et al., 2018). Additionally, there is a discrepancy between people with PD and their spousal caregivers on preferences of nursing home placement as an acceptable option (Habermann & Shin, 2016). Thus, there is a need to assist family caregivers in providing care for people with advanced PD in a home setting.

### 4.1. Limitations for this study

This study adds to the literature that describes dyads' perspectives on symptom progression in the advanced stages of PD. However, the severity and frequencies of those reported symptoms were not assessed due to the nature of the study. Participants in this study included 15 dyads who were relatively well-educated, having completed a mean of 15.8 years of formal education; due to their homogeneity, these findings are not intended to be generalized to other advanced PD populations. Furthermore, this study is a secondary analysis of pre-existing qualitative data obtained during a mixed-methods study (Habermann et al., 2019). Although informational redundancy was reached in the parent study, member checking was not conducted in this study due to the nature of the study. While a six-month time lapse was appropriate for the purposes of the original study, it did not allow sufficient time for the emergence of clinically significant symptom progression within this study.

## 5. Conclusion

The presence of multiple, compounding symptoms present challenges for maintaining safety in the home. Understanding dyads' perspectives on the trajectory of advanced PD is important for the provision of appropriate care and resources in their home settings, helping to prevent hospitalization and institutionalization. Future research that addresses the severity and frequency of reported symptoms and explores symptom clusters could further enrich our understanding of symptom progression in advanced PD and inform nursing care in this population. As the elapse of six months did not adequately capture meaningful symptom progression in advanced PD, future studies could benefit from the adoption of a longitudinal approach.

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