

# The Symptom Experience of Patients with Parkinson's Disease

Jane H. Backer



**A**bstract: Studying the symptom experience of persons with Parkinson's disease (PD) could aid in determining the extent to which particular symptoms and symptom dimensions pose a problem and could assist in determining which of these to target for interventions. A descriptive correlational design with face-to-face interviews was used to study the extent of distress related to 13 symptoms of PD and relationships among symptom intensity, frequency, duration, and distress in 85 persons with PD. The mean number of symptoms reported was 7. The most distressing symptom was off time, followed by freezing gait, postural instability, sleep disturbance, and difficulty concentrating. Mean symptom distress scores ranged from slightly less to more than moderately. Symptom intensity and distress were strongly correlated, whereas the relationships of symptom frequency and duration to distress varied by symptom. Symptoms found in this study to be most distressing should be considered when interventions are being developed. It is likely that distress does make symptoms worse, so it is important to assess symptom intensity, duration, and frequency as well as distress when interventions to reduce distress are evaluated.

More than 1 million people in the United States have Parkinson's disease (PD). The prevalence of the disease is expected to increase in the future as Americans age, because the disease primarily affects older adults (Lang & Lozano, 1998). A slowly progressive neurodegenerative disorder, PD is characterized by symptoms of bradykinesia, tremor, rigidity, and postural instability. As the disease progresses, individuals experience additional symptoms such as freezing gait, difficulty swallowing, drooling, and voice softening. From day to day, a person may experience extreme fluctuations in the severity of his or her symptoms that are difficult to predict and control. Such fluctuations in symptoms are likely to be accompanied by declines in functioning (Marr, 1991; Mizuno, Kondo, & Mori, 1994), psychological well-being (Wallhagen & Brod, 1997), and quality of life (QOL; Bushnell & Martin, 1999; Frazier, 2000; Schrag, Jahanshahi, & Quinn, 2000). In addition, PD symptoms are predictors of higher patient depression scores (Schrag, Jahanshahi, & Quinn, 2001) and greater caregiver distress (Aarsland, Larsen, Karlsen, Lim, & Tandberg, 1999).

Questions or comments about this article may be directed to Jane H. Backer, DNS RN CNS, 317/274-3944 or at [jabacke@iupui.edu](mailto:jabacke@iupui.edu). She is an associate professor at Indiana University School of Nursing, Indianapolis, IN.

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A 5-year review of literature on stressors in the chronically ill revealed that symptoms were one of the most frequently identified stressors (Frost, Werner, & Orth, 1998). Indeed, persons with PD view their symptoms as so distressing and embarrassing that they often withdraw from social contact (Backer, 2000; Brod, Mendelson, & Roberts, 1998; Frazier, 2000; Marr, 1991). *Symptom distress* is defined as the extent to which a person is bothered by a symptom (Lenz, Pugh, Miligan, Gift, & Suppe, 1997). Two studies (Brod et al.; Frazier) measured whether specific symptoms were perceived as stressful among persons with PD, but neither study provided information about the level of symptom distress. Thus, the extent to which various symptoms are distressing is unknown.

A symptom is conceptualized as a multidimensional experience that includes dimensions of distress, intensity, timing, and quality (Lenz et al., 1997). Although symptoms are multidimensional, studies of PD symptoms have generally assessed only one dimension. Assessing multiple dimensions of a construct is important because particular interventions might effectively improve one dimension but not another. It is also possible that in improving one dimension of a symptom, another dimension could be affected. For example, decreasing symptom distress could have a positive effect on symptom intensity, timing, or both.

Studying symptom distress and the relationships among the different symptom dimensions could aid in determining the extent to which each symptom poses a problem to patients and assist in determining which symptoms and symptom dimensions to target for interventions. The purposes of this study were to (a) describe the extent of distress related to 13 PD symptoms and (b) examine the relationships among symptom intensity, frequency, duration, and distress among persons with PD.

## Review of Literature

Measurement of PD symptoms has varied greatly, and this lack of standardized measurement has hindered comparisons of research findings. In general, symptoms have been measured by observer ratings of the presence or absence of symptoms (e.g., Hoehn and Yahr test) or a measure that combined observer ratings and subjective reports of symptom severity (e.g., Unified Parkinson's Disease Rating Scale). These observer ratings of symptoms, however, failed to take into account how patients measure symptoms for themselves. In addition, measuring one dimension of a symptom, such as its severity, does not

adequately capture the entire symptom experience, which is multidimensional (Dodd et al., 2001; Lenz et al., 1997). For this study, symptoms were defined as subjective experiences that have several dimensions, including intensity (strength or severity), timing (duration and frequency of occurrence), and distress (the extent to which symptoms are bothersome or worrisome; Lenz et al.).

Abudi, Bar-Tal, Liv, and Fish (1997) studied the presence of 39 symptoms and their severities in a small ( $N = 39$ ) PD sample. The symptoms were categorized into one of four categories: motor, mental, psychosocial, and non-specific. The most severe motor symptoms reported, in order of greatest severity, were tremor/dyskinesia, writing, changing positions, walking outside home, fatigue, muscle ache, freezing gait, and muscle cramps. Mental symptoms in order of severity were impaired memory, mental confusion, and deficit in cognitive sequencing. The most severe psychosocial symptoms were social interactions, strain/stress, verbal communication, and shame. In the nonspecific category, the most severe were bowel problems, insomnia, and vague aches.

Although the problems within the categories were labeled symptoms by the researchers, the concept of symptom was not specifically defined. Many of the problems labeled as symptoms related to activities of daily living that can be adversely affected by symptoms such as difficulty with writing, dressing oneself, or getting in and out of bed. Symptom frequency was used as an indicator of severity, although frequency and severity may not be the same concepts. Furthermore, mean frequency scores were determined by including all the patients in the computation rather than by including only participants who actually experienced a symptom. This factor could have lowered the mean symptom-severity scores and led to misleading results.

Schrag et al. (2000) studied 92 persons with PD to determine factors predictive of QOL. Such factors included postural instability, hallucinations, falls, gait impairment, dyskinesia, orthostatic hypotension, insomnia, pain, and speech and swallowing impairments. Measures of symptoms were both objective and subjective. Postural instability, assessed by an observer rating, was the only significant predictor of QOL, accounting for 5% of the variance. The remaining symptoms, measured by self-report of their presence, were not significant predictors. Simply reporting the presence of a symptom does not help in understanding the symptom experience and may not be adequate to explain the contributions of symptoms to self-reported QOL.

Backer (2000) described the illness-related stressors of 70 individuals with PD by using an open-ended question and examined the extent to which social support and coping responses predicted physical and psychosocial health dysfunction. Although a variety of stressors were reported, symptoms of PD were among the major stressors of study

participants. In addition, participants were asked to indicate whether stress made their symptoms worse and to what extent. Responses indicated that 57 of 63 persons with PD experienced a 50% or greater increase in the severity of their symptoms during times of stress.

Two studies examined the perceived stressfulness of symptoms among persons with PD. Brod et al. (1998) studied patients' ( $N = 101$ ) experiences of PD using structured interviews. As part of the study, patients were asked to indicate how severe and how bothersome (stressful) were each of 39 problems that included symptoms of PD, as well as functional and psychosocial problems. Across the 39 problems, the correlations between severity and stressfulness were 0.92 or higher. Correlations were similar at the item level, so only the severity scores were analyzed. Researchers interpreted findings as indicating that symptoms of rigidity, postural instability, tremor, forgetfulness, difficulty sleeping, and slowness in thinking were among the problems reported as most severe by patients; more than 50% of the patients experienced each of these symptoms. The high correlation between symptom severity and stressfulness suggests that the severity of symptoms almost completely determined stressfulness or, more likely, that the patients were not differentiating between the dissimilar meanings of the two variables.

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Frazier's (2000) findings were similar to the findings of Brod et al. (1998) in relation to the particular symptoms reported as most stressful. Frazier examined three categories of symptoms (physical, cognitive, and psychosocial) in 145 patients with PD. Patients were asked to select the most stressful symptom in each of the three categories from a list of symptoms. Seventeen percent of the patients indicated tremor was the most stressful physical symptom, followed by rigidity (14%), falling (11%), and getting up from a chair (11%). More than 26% of patients indicated that a lack of mental energy was the most stressful cognitive symptom, followed by difficulty sleeping (14%), forgetfulness (13%), and slowed thinking processes (11%). The most stressful psychosocial symptoms were dependence on others (21%), feelings of being a burden (17%), depression (15%), and loss of control (14%).

The studies by Abudi, Bar-Tal, Ziv, and Fish (1997) and Schrag et al. (2000) examined the self-reported presence of symptoms among persons with PD. Abudi et al. also examined symptom severity. Weaknesses associated with the studies were the limited number of symptom dimensions examined and the failure to distinguish between

participants who experienced a particular symptom and those who did not when reporting descriptive findings (Abdui et al.). Backer (2000) found that the presence of stress exacerbates symptoms. Brod et al. (1998) and Frazier (2000) examined symptom stressfulness, although the definitions of the concept were not always clear. Both studies of symptom stressfulness found that rigidity, postural instability/falls, tremor, difficulty sleeping, forgetfulness, and slowed thinking were among the most stressful symptoms. Frazier, however, did not ask the extent to which the symptoms were stressful; and the measure of stressfulness in the Brod et al. study was so highly correlated with symptom severity that it was not included in the data analysis.

## Method

This study addresses the gaps in knowledge by examining five dimensions (presence, intensity, duration, frequency, and distress) of 13 common symptoms of PD consistent with the conceptualization of a symptom as a multidimensional construct. Only data from participants who experienced the symptom were included in the statistical analyses. In addition, the relationships among the symptom dimensions were examined to assess whether one symptom dimension, such as symptom distress, affects other symptom dimensions. To ensure clarity in the meaning of the different symptom dimensions, the symptom measures were pilot tested. The results indicated participants were able to distinguish differences in meaning among the symptom dimensions.

The research questions for this study were the following: (a) What are the most distressing symptoms among persons with PD? (b) What are the relationships among symptom frequency, duration, intensity, and distress?

## Design and Sample

A descriptive correlational design was used. A convenience sample of 93 persons diagnosed with idiopathic PD was recruited from a movement-disorder outpatient clinic in a large, urban teaching hospital. Sample inclusion criteria were a medical diagnosis of idiopathic PD confirmed by a neurologist experienced in the treatment of patients with PD; absence of comorbid conditions that affect movement; and a score of 24 or higher on the Mini-Mental State Examination (MMSE; Folstein, Folstein, & McHugh, 1975). Eight persons were excluded from the study

for the following reasons: four scored below 24 on the MMSE; two had severe speech problems that prevented them from participating; and two had considerable data missing. These eight persons did not differ significantly from the remaining sample in demographics or stage of disease. The final sample of 85 participants comprised 54 men and 31 women, aged 42–88 years ( $M = 66$  years;  $SD = 9.9$ ). All participants were White; most were married ( $n = 56$ ) and retired ( $n = 53$ ); and almost 60% had education beyond high school. More than half (54%) of the participants were in the middle stage of PD, scoring from 2.5 to 3.0 on the Hoehn and Yahr scale (Hoehn & Yahr, 1967), which ranges from 0 to 5. This scale is frequently used clinically and in PD research, with stage of disease determined by rater observation of physical signs. Ten participants (12%) were in the more advanced stages of disease, scoring from 4 to 5 on the Hoehn and Yahr scale, with two of the 10 scoring 5 (i.e., wheelchair or bed bound).

## Measurement

The author developed the Symptom Experience Questionnaire based on Lenz et al.'s (1997) conceptual definitions of the symptom experience dimensions. Thirteen symptoms of PD were measured by patient self-report on five dimensions—presence, frequency, duration, intensity, and distress. The 13 symptoms were selected because they are commonly experienced by patients and are representative of the various disease stages. In addition, the number of symptoms was limited to prevent subject response fatigue. Participants first reported whether they had experienced each of the 13 symptoms over the past 7 days, not including the day of the interview, and then indicated the frequency, duration, intensity, and distress of each experienced symptom (see Table 1 for symptoms and response sets). Content validity of the symptom experience measures was supported by 100% agreement about relevance of the items among 10 persons with PD and two experts in the treatment of PD.

**Table 1. Symptoms and 1-Item Measures of Frequency, Duration, Intensity, and Distress**

Symptoms	
Participants were asked whether they experienced each of the following symptoms: unilateral hand tremor, bilateral hand tremor, rigidity, bradykinesia, freezing, off times, postural instability, voice softening, dyskinesia, difficulty swallowing, drooling, difficulty sleeping, and difficulty concentrating on tasks. For each symptom present, the following questions were asked. (A score of zero was assigned if a symptom was not present.)	
<b>Frequency</b>	How often did you experience the symptom? (1 = less than 1/week; 2 = 1–2/week; 3 = 1–2/day; 4 = several times/day; 5 = continuously)
<b>Duration</b>	How long did the symptom usually last? (1 = few minutes; 2 = several minutes to 1 hour; 3 = several hours; 4 = all day or all night; 5 = continuously)
<b>Intensity</b>	Usually how severe was the symptom when it occurred? (1 = very mild; 2 = mild; 3 = moderate; 4 = severe; 5 = very severe)
<b>Distress</b>	To what extent was the symptom bothersome or distressing? (1 = not at all; 2 = a little; 3 = moderately; 4 = extremely)

**Table 2. Means and Standard Deviations of Symptom Distress, Intensity, Frequency, and Duration Among Persons Experiencing Symptom\***

Symptom	Distress			Intensity			Frequency			Duration		
	<i>M</i>	<i>SD</i>	<i>n</i>	<i>M</i>	<i>SD</i>	<i>n</i>	<i>M</i>	<i>SD</i>	<i>n</i>	<i>M</i>	<i>SD</i>	<i>n</i>
Off time	3.2**	0.81	34	3.3	0.98	32	3.0	0.83	34	2.0	0.56	33
Freezing gait	2.9	1.1	38	3.2	1.2	35	2.9	0.84	37	1.4***	0.60	37
Postural Instability	2.9	0.88	63	2.7	1.1	58	3.0	1.1	61	1.6	1.2	62
Sleep disturbance	2.9	0.97	40	3.5**	1.0	35	3.3	1.3	38	3.0	0.83	38
Concentration difficulty	2.9	0.90	44	2.8	0.84	40	3.3	1.1	43	2.5	1.4	41
Bilateral hand tremor	2.8	1.0	20	3.1	1.1	19	3.5	1.1	20	2.4	1.5	20
Bradykinesia	2.8	0.86	67	2.9	0.96	62	3.7	1.1	67	2.9	1.6	67
Swallowing difficulty	2.8	0.87	40	2.5***	1.0	35	2.8***	1.0	40	1.5	1.0	40
Dyskinesia	2.8	1.0	40	2.8	1.3	37	2.8***	0.84	39	1.8	0.87	39
Drooling	2.7	1.0	47	2.6	1.1	45	3.1	1.2	47	2.5	1.5	47
Rigidity	2.6***	0.91	65	2.9	0.85	60	3.2	1.1	64	2.1	1.2	65
Voice softening	2.6***	1.1	60	2.8	1.1	55	3.9**	1.1	58	3.2**	1.5	58
Unilateral hand tremor	2.6***	0.88	43	2.6	1.0	40	3.4	1.0	43	2.2	1.4	42

\*Unequal numbers across the dimensions of a symptom are because of missing data.

\*\*Indicates highest mean in each category.

\*\*\*Indicates lowest mean in each category.

Note: Response range for symptom distress is 1–4, and, for remaining dimensions, 1–5.

## Procedure

After institutional review board approval, letters signed by their physician were sent to potential study participants. The letters included a description of the study and requested permission for a researcher to contact him or her. Upon permission, a researcher contacted potential participants by telephone to screen for eligibility (except administration of the MMSE), obtain verbal informed consent for participating in the study, and schedule a face-to-face interview. Interviews were conducted in a private room of an outpatient clinic before or after the participants saw their physician. The researcher or a research assistant (who was trained in the data collection procedures) collected data. Written informed consent was obtained; then the MMSE was administered to validate the absence of dementia, followed by the Hoehn and Yahr scale to assess disease stage. Because persons with PD commonly experience difficulty writing, the Symptom Experience Questionnaire was read and marked by the data collector as participants followed with a copy. The data used for this study were part of a larger study of symptom experience, coping, and functioning among persons with PD. Data collection for the larger study took approximately 1½ hours to complete. A 10-minute break was offered at midpoint to prevent participant fatigue.

## Data Analyses

Descriptive statistics were used to describe the various dimensions of the symptoms of PD. Because the data were

not normally distributed, the Spearman rho correlation was used to determine relationships among symptom frequency, duration, intensity, and distress, using data only from persons who were experiencing that symptom.

## Results

All participants reported at least one symptom (ranging from 1 to 12 symptoms). The mean number of symptoms was seven (*SD* = 2.7), with 12 participants (14%) reporting four or fewer symptoms and 16 (19%) reporting 10 or more symptoms. Symptoms experienced by most participants were bradykinesia (79%), rigidity (76%), postural instability (74%), and unilateral or bilateral hand tremor (74%).

Table 2 shows the mean and standard deviation of symptom distress, intensity, frequency, and duration among participants who had that symptom. In regard to research question 1, the most distressing symptom, on average, was “off time” (when movement is greatly impaired or absent), followed (in order) by freezing gait, postural instability, sleep disturbance, and difficulty concentrating, all four of which had similar mean distress scores. All the symptoms, on average, were more than a little distressing, but only off time was more than moderately distressing. A post hoc analysis using MANOVA was conducted to examine differences in symptom distress according to stage of disease. Mean symptom distress scores were significantly higher for five symptoms in patients in middle to late stages of

disease (i.e., Hoehn and Yahr scores of 3 to 5;  $n = 55$ ) compared with early stages (i.e., Hoehn and Yahr scores from 1 to 2.5;  $n = 30$ ). Although not statistically significant, all the remaining mean symptom distress scores, with the exception of unilateral hand tremor, were also higher for patients in middle to late stages of disease.

The symptoms with greatest intensity, in order of intensity, were sleep disturbance, off time, freezing gait, and bilateral hand tremor. Voice softening occurred the most frequently, followed by bradykinesia, bilateral hand tremor, and of equal frequency to each other, sleep disturbance and difficulty concentrating. Voice softening was also of longest duration, followed by sleep disturbance, bradykinesia, and, of equal duration, difficulty with concentration and drooling.

For the statistical analyses for research question 2, data derived only from participants reporting the presence of the symptom were used. Significance was set at  $p < .05$ . Spearman rho correlations indicated that symptom intensity was significantly related to symptom distress in all but two symptoms—bilateral hand tremor and rigidity (Table 3). Symptom frequency and duration were positively and significantly related to symptom distress for symptoms of freezing gait, postural instability, swallowing, dyskinesia, and unilateral hand tremor. In addition, frequency of uncontrollable drooling was positively and significantly related to the distress caused by that symptom. Symptom frequency was positively and significantly related to symptom duration in all but two symptoms, sleep and off time. Symptom frequency and duration were, for the most part, more strongly related to symptom intensity than to symptom distress.

## Discussion

In this study exploring the dimensions of 13 common PD symptoms, most of the participants experienced a number of symptoms. The most frequently reported symptoms were ones that are classic for PD: bradykinesia, rigidity, postural instability, and hand tremor. The most frequently reported symptoms, however, were not the most distressing. This finding supports the caution of Frost et al. (1998) against assuming that the most frequently occurring symptoms will be the most distressing. Three of the five most distressing symptoms (i.e., postural instability, sleep disturbance, and difficulty concentrating) were also among the most stressful in studies by Brod et al. (1998) and Frazier (2000). Off time, however, the most distressing symptom in this study, was not included in the two earlier studies of symptom distress. The mean distress score for off time was between *moderately* and *extremely* distressing. The mean distress scores for the remaining symptoms were all similar and in the range of slightly less than *moderately* distressing.

**Table 3. Spearman Rho Correlations Among Dimensions of Each Symptom**

Variable	Intensity	Frequency	Duration
Off time			
Distress	0.53**	0.22	-0.02
Intensity		0.41*	0.28
Frequency			0.21
Freezing gait			
Distress	0.75**	0.59**	0.47**
Intensity		0.41*	0.61**
Frequency			0.45**
Postural instability			
Distress	0.63**	0.30*	0.46**
Intensity		0.50**	0.43**
Frequency			0.50**
Sleep			
Distress	0.34*	0.14	0.14
Intensity		0.34*	0.27
Frequency			0.31
Concentration			
Distress	0.52**	0.18	0.16
Intensity		0.26	0.26
Frequency			0.68**
Bilateral tremor			
Distress	0.40	0.32	0.36
Intensity		0.43	0.48*
Frequency			0.69**
Bradykinesia			
Distress	0.70**	0.16	0.22
Intensity		0.13	0.20
Frequency			0.50**
Swallowing			
Distress	0.55**	0.48**	0.39*
Intensity		0.15	0.26
Frequency			0.50**
Dyskinesia			
Distress	0.82**	0.58**	0.54**
Intensity		0.70**	0.43**
Frequency			0.59**
Drooling			
Distress	0.48**	0.47**	0.13
Intensity		0.62**	0.43**
Frequency			0.54**
Rigidity			
Distress	0.21	0.19	0.10
Intensity		0.20	0.32*
Frequency			0.44**
Voice			
Distress	0.42**	-0.01	-0.07
Intensity		0.40**	0.28*
Frequency			0.80**
Unilateral tremor			
Distress	0.50**	0.38*	0.39*
Intensity		0.49**	0.55**
Frequency			0.61**

\* $p < .05$ , \*\* $p \leq .01$ .

As might be expected, respondents appeared to experience more symptom distress as the disease progressed. Four of the five most distressing symptoms were ones that are generally experienced by individuals in the moderately advanced and advanced stages of disease—off time, freezing gait, sleep disturbance, and difficulty concentrating. Furthermore, the remaining symptom, postural instability, though present in the early stage of disease, worsens as the disease progresses. The suggestion of the evidence that the extent of symptom distress is higher in later stages of PD than in earlier stages is important because studies of symptom distress in patients with PD (e.g., Brod et al., 1998; Frazier, 2000) have largely comprised persons in the early to middle stages of disease, as was the case in this study. Persons in the later stages of PD, who are likely to have the greatest symptom distress, have been underrepresented in studies.

It is likely that distress does make symptoms worse. Symptom distress was strongly related to symptom intensity, although a cross-sectional design does not allow causal conclusions. Correlations were much lower, however, than those of Brod et al. (1998), who found correlations above 0.90. Assessing both symptom distress and intensity may not be necessary for some symptoms, such as freezing gait and dyskinesia, that had very high correlations between distress and intensity (i.e., 0.75 and 0.82, respectively).

The respective relationships of symptom frequency and duration to distress appear to be selective and based on the type of symptom. For example, symptom frequency and duration were significantly and moderately related to distress in five symptoms: freezing gait, postural instability, dyskinesia, unilateral hand tremor, and swallowing. There were no significant associations among symptom frequency, duration, and distress in the remaining symptoms, with one exception: the frequency of drooling was significantly associated with distress. Also, symptom intensity may moderate the influence of symptom distress on frequency and duration. Findings indicated that symptom frequency and duration were, for the most part, more strongly related to symptom intensity than symptom distress.

The associations among the symptom dimensions were relatively stronger between symptom distress and intensity and between symptom frequency and duration. Symptom distress and intensity perceptions are probably more subjective than ratings of symptom frequency and duration; this factor may account for the differences in strength of associations.

## Nursing Implications

Most patients in this study experienced a number of symptoms. Thus, nurses need to include the multiple symptoms that can accompany PD in their patient assessments. Asking patients about the intensity, frequency, and duration of their symptoms as well as the

distress associated with the symptoms is also important to understanding their complete symptom experiences, determining symptoms to target for intervention, and evaluating intervention effectiveness. Considering that PD is a chronic, progressive disease, an intervention is unlikely to completely eliminate a symptom. However, psychosocial or other nursing interventions could, for example, lead to decreases in symptom distress and symptom intensity that would not be apparent if only the presence or absence of a symptom was assessed.

Symptoms of off time, freezing gait, postural instability, sleep disturbance, and difficulty concentrating may be the most distressing symptoms to patients, and thus nurses may want to consider these symptoms as the first to be targeted for intervention. For example, thinking through ways to manage an off period when in public may alleviate distress associated with the symptom and enhance participation in social activities. Empirical evidence indicates that observable PD symptoms are embarrassing to patients in social situations and often lead to social withdrawal (Backer, 2000; Marr, 1991). Off periods, specifically, have been accompanied by feelings of doom, helplessness, and hopelessness (Matson, 2002).

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### *Difficulty with sleep requires further assessment before an intervention is implemented.*

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Interventions targeting symptoms of freezing (i.e., temporary interruption of forward movement) and postural instability are likely to be important not only because they are distressing to patients but also because research evidence indicates that freezing and postural instability are associated with increased risk of falls (Gray & Hildebrand, 2000). Difficulty with sleep requires further assessment to determine the type of sleep problem and possible etiologies before an intervention is implemented. Nighttime sleep interruption is a common problem among persons with PD and is associated with nocturia, rigidity, pain, and difficulties turning over in bed (Dowling, 1995).

## Limitations and Recommendations

Further studies about the symptom experiences of persons with PD are needed to address a greater number of PD symptoms than those included in this study. Another limitation was the small number of participants in the late stage of PD, which limits the generalizability of study findings. Study samples need to include more persons with advanced PD, because persons in the advanced stage of PD are more likely to experience symptoms that are highly distressing than those in an earlier stage of PD. The lack of reliability and validity of the 1-item measures used in this study was an additional limitation. A multi-dimensional measure of the PD symptom experience of patients, with established reliability and validity, is

needed. Finally, because of the cross-sectional design, the causal direction of the relationships among the study variables could not be determined. Longitudinal studies are needed to explicate the causal direction of the relationships among the symptom dimensions.

## Summary

This study examined the symptom experience of a convenience sample of 85 persons with PD. The most distressing symptoms were off time, freezing gait, postural instability, sleep disturbance, and difficulty concentrating. Symptom distress was strongly related to symptom intensity. Symptom distress was also related to symptom frequency and duration, although the relationships varied with to the type of symptom and were not as strong as the association between symptom distress and intensity. The findings indicated that symptom distress might make symptoms worse. Thus, neuroscience nurses providing care for patients with PD need to assess symptom intensity, duration, and frequency, as well as distress, when implementing interventions.

## Acknowledgment

The author thanks Nancy Dayhoff, EdD RN CNS, for her valuable contributions to the study and Phyllis Dexter, EdD RN CNS, for her assistance during the preparation of the manuscript.

## References

- Aarsland, D., Larsen, J. P., Karlsen, K., Lim, N. G., & Tandberg, E. (1999). Mental symptoms in Parkinson's disease are important contributors to caregiver distress. *International Journal of Geriatric Psychiatry, 14*, 866-874.
- Abudi, S., Bar-Tal, Y., Ziv, L., & Fish, M. (1997). Parkinson's disease symptoms: Patients' perceptions. *Journal of Advanced Nursing, 25*, 54-59.
- Backer, J. H. (2000). Stressors, social support, coping, and health dysfunction in individuals with Parkinson's disease. *Journal of Gerontological Nursing, 26*(11), 7-16.
- Brod, M., Mendelsohn, G. A., & Roberts, B. (1998). Patients' experiences of Parkinson's disease. *Journal of Gerontology, 53B*(4), 213-222.
- Bushnell, D. M., & Martin, M. L. (1999). Quality of life and Parkinson's disease: Translation and validation of the U.S. Parkinson's Disease Questionnaire (PDQ-39). *Quality of Life Research, 8*, 345-350.
- Dodd, M., Janson, S., Facione, N., Faucett, J., Froelicher, E. S., Humphreys, J., et al. (2001). Advancing the science of symptom management. *Journal of Advanced Nursing, 33*, 668-676.
- Dowling, G. A. (1995). Sleep in older women with Parkinson's disease. *Journal of Neuroscience Nursing, 27*, 355-362.

- Folstein, M., Folstein, S., & McHugh, P. (1975). Mini-Mental State: A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research, 12*, 189-198.
- Frazier, L. D. (2000). Coping with disease-related stressors in Parkinson's disease. *Gerontologist, 40*(1), 53-63.
- Frost, M. H., Werner, J. S., & Orth, K. (1998). Symptom distress: What is the clinical significance? *Connection, 14*(2), 8.
- Gray, P., & Hildebrand, K. (2000). Fall risk factors in Parkinson's disease. *Journal of Neuroscience Nursing, 32*, 222-228.
- Hoehn, M., & Yahr, M. (1967). Parkinsonism: Onset, progression, and mortality. *Neurology, 17*, 427-442.
- Lang, A. E., & Lozano, A. M. (1998). Parkinson's disease. *New England Journal of Medicine, 339*, 1044-1053.
- Lenz, E. R., Pugh, L. C., Milligan, R. A., Gift, A., & Suppe, F. (1997). The middle-range theory of unpleasant symptoms: An update. *Advances in Nursing Science, 19*(3), 14-27.
- Marr, J. (1991). The experience of living with Parkinson's disease. *Journal of Neuroscience Nursing, 23*, 325-329.
- Matson, N. (2002). Made of stone: A view of Parkinson 'off' periods. *Psychology and Psychotherapy: Theory, Research, and Practice, 75*, 93-99.
- Mizuno, Y., Kondo, T., & Mori, H. (1994). Various aspects of motor fluctuations and their management in Parkinson's disease. *Neurology, 44*(Suppl. 6), S29-S34.
- Schrag, A., Jahanshahi, M., & Quinn, N. (2000). What contributes to quality of life in patients with Parkinson's disease? *Journal of Neurology, Neurosurgery, and Psychiatry, 69*, 308-312.
- Schrag, A., Jahanshahi, M., & Quinn, N. (2001). What contributes to depression in Parkinson's disease? *Psychological Medicine, 31*(1), 65-73.
- Wallhagen, M. L., & Brod, M. (1997). Perceived control and well-being in Parkinson's disease. *Western Journal of Nursing Research, 19*(1), 11-31.

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