PARKINSONALLIANCE

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Sleep & Fatigue in Parkinson's Disease

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SUMMARY

Sleep disturbances and fatigue are major problems in patients with Parkinson's disease (PD). We surveyed 433 people with Parkinson's disease to look at sleep habits, sleep quality and fatigue. We found that a majority of people reported moderate sleep problems. Factors such as mild depression and anxiety were associated with poor sleep. When looking at fatigue, those classified as good sleepers reported the least amount of fatigue.

Of the healthy habits surveyed, those that reported exercising daily had the lowest reported fatigue. The attached report further describes these results.

INTRODUCTION

Sleep disturbances and fatigue are major problems in patients with Parkinson's disease. The major sleep disturbances associated with PD include REM behavioral sleep disorder and sleep fragmentation. Fatigue is also very common in PD with a prevalence of 50%. We surveyed 433 people with Parkinson's disease to look at sleep habits, sleep quality and fatigue.

Sleep:

• Sleep disturbances at all levels are common in Parkinson's disease. Problems with regulation of sleep and wakefulness cycles results in insomnia and daytime sleepiness. Additionally, impaired control of motor activity during sleep results in REM behavioral sleep disorder and sleep fragmentation. These factors contribute to disturbed sleep in virtually all patients with PD, with one survey suggesting this number is as high as 98%. ^{1,2}

Fatigue:

- Fatigue is a common non-motor symptom of Parkinson's disease that is present at all stages of PD. Fatigue can disrupt daily activities and may worsen as PD progresses. There is currently no consensus on pharmacological treatments that reduce fatigue. Generally, healthy habits are recommended to patients experiencing fatigue. ³
- Both sleep disturbances and fatigue are unmet needs in PD. This survey was designed to gain information about sleep and fatigue with the following objectives:

OBJECTIVES

- To gain insights about the person with Parkinson's disease subjective report of sleep difficulties and fatigue.
- To provide information pertaining to modifiable factors that may increase sleep quality and reduce fatigue.

METHODS/INSTRUMENT DESCRIPTION

The Parkinson Alliance Demographic Questionnaire:

The Parkinson Alliance Demographic Questionnaire includes items related to demographics (age, gender, race, marital status, education, etc.) and pertinent items known to have a relationship with sleep quality, such as naps, exercise, depression, anxiety, deep brain stimulation, medications for sleep disturbance, and healthy sleep habits.

Parkinson's Disease Sleep Scale – 2

(PDSS-2; Chaudhuri, Pal, Di Marco, et al, 2002; Trenkwalder, et al., 2010).

The PDSS-2 consists of 15 questions about various sleep and nighttime sleep disturbances. Response options to the sleep-related symptoms range from 0 to 4, with 0 being "never" and 4 being "very often." The PDSS-2 total score ranges from 0 (no disturbance) to 60 (maximum nocturnal disturbance). There are 3 sub-categories in this questionnaire Motor Symptoms, Parkinson's Disease Symptoms at Night, and Disturbed Sleep, with score ranges from 0 to 20. Higher scores reflect greater nighttime sleep disturbance.

Fatigue Severity Scale (FSS; Krupp, et al., 1989):

The FSS is a 9-item questionnaire that focuses on the impact of fatigue on an individual's daily functioning. The response options were modified into three categories for this survey: disagree, neutral, and agree, where disagree=1, neutral=2, and agree=3. Higher scores indicate greater levels of fatigue.

Factors to consider when interpreting the results:

This study used a survey-based methodology. Generalizability of the results may be limited. Sample sizes noted in the sections below may vary somewhat within specific groups (e.g., poor sleepers vs good sleepers) and some individuals may not have responded to a specific question. Importantly, the subjective report in this survey serves to highlight the "patient's perspective" about his or her experience with perceived sleep disturbances, fatigue and quality of life.

RESULTS

- The summary of the demographic information and clinical characteristics of the participants in this study can be found in Table 1.
 - o 54% male
 - o 94% white/Caucasian
 - 97% currently residing in the US with 45% (195 respondents) reported from the mid-Atlantic east coast (NJ, NY, PA)
 - o 60% of respondents reported having a college education or graduate degree
 - o 70% report being married
 - 82% living with someone at the time of survey
 - o 38% classified as early onset PD with a diagnosis prior to 60 years of age
 - 0 75% report provider is neurologist specializing in movement disorders

Table 1: Demographics and Clinical Features of the Participants

		(Mean, Range, and percentage)	
Age		72 years with a range of 37 to 93	
Age at PD Diagnosis		60 years with a range of 23 to 88	
Duration of PD		11 years with a range of 0 to 42	
Male		54%	
Female		46%	
Married		70%	
Lives with Someone		82%	
Ethnicity			
	Caucasian	94%	
	African American	1%	
	Hispanic	3%	
	Other	2%	
Education			
	<12 years	4%	
	High School	10%	
	Some College/Associates Degree	25%	
	College Degree	28%	
	Graduate/Advanced Degree	33%	

SUBJECTIVE SLEEP DIFFICULTIES

Figure 1: Participants Reporting Sleep Difficulties

- Fifty-three percent of respondents reported at least moderate sleep disturbances as measures by the PDSS.
- Based on figure 1, most people surveyed report moderate sleep problems. (Table 1 represents data found in figure 1)



• The PDSS can be broken down into sub-domains that measure motor symptoms at night, PD symptoms at night and sleep disturbances. Each sub-domain has a total possible score of 20.

Figure 2: Sleep Disturbances Categorized into Motor Symptoms, PD Symptoms or Disturbed Sleep.

• Respondents scored higher in the disturbed sleep domain compared to motor symptoms and PD symptoms. (Figure 2 shows median scores for these three subdomains)



Sleep Disturbance Sub-scores that 50% of Respondents Reported



Good and Poor Sleepers

- Respondents were grouped into "good sleepers" and "poor sleepers" based on PDSS.⁴
- The PDSS total score ranges from 0 to 60 with a score of 14 or lower classified as good sleeper and 15 or higher classified as poor sleeper. Overall, 66% (285 respondents) were classified as poor sleepers and 148 (34%) as good sleepers.

Figure 3: The Association Between Sleep Quality and Anxiety & Depression

• Figure 3 shows depression or anxiety in past two weeks in good vs poor sleepers. Depression and anxiety trended similarly with sleep quality. This suggests increased mild depression and anxiety is associated with poor sleep or vice versa.



DEPRESSION	Good Sleeper (142 respondents)	Poor Sleeper (283 respondents)
No Depression	75	83
Mild Depression	44	142
Moderate to Severe Depression	23	58

ANXIETY	Good Sleeper (143 respondents)	Poor Sleeper (283 respondents)
No Anxiety	60	71
Mild Anxiety	53	128
Moderate to Severe Anxiety	30	84

Fatigue:

• Fatigue overall scores on the 9-point scale range from 0 to 9. Respondents were grouped by scores (0 to 3 little to no fatigue reported; 4 to 6 moderate fatigue; 7 to 9 severe fatigue).



Figure 4: Fatigue Experienced by Respondents



FATIGUE	Good Sleeper (148 respondents)	Poor Sleeper (285 respondents)
No Fatigue	92	93
Moderate Fatigue	29	97
Severe Fatigue	27	95

Figure 6: How Do Modifiable Sleep Habits Tie In?

• The percentage of respondents that reported participating in the healthy sleep habit.

Healthy sleep habits measured included:	Percentage	Number of Respondents
Avoid eating before bed	84%	365
Avoid caffeine/nicotine/alcohol before bed	81%	351
Cool room	80%	348
Having a nighttime routine	80%	347
Hydration	73%	317
Avoid stimulating activities before bed (TV/Screens)	70%	302
Having a bedtime routine	69%	297
Dark room	64%	276
Regular daily exercise	59%	256
Having a waketime	46%	201
Use relaxing activities	33%	144

Figure 7: Association Between Exercise and Fatigue



Additional analyses: This subgroup had the following characteristics—majority bilateral stimulators in subthalamic nucleus (SN). 37% reported DBS improves their sleep moderately to extremely while 36% report that there were no changes in their sleep with DBS. In this small group, there is no evidence that deep brain stimulation is associated with sleep improvement or increased sleep disturbances.

CONCLUSION

Fatigue and sleep disturbances are common in PD. Patients with good sleep quality aka "good sleepers" reported less fatigue compared to poor sleepers. Poor sleepers reported higher levels of anxiety and depression. Of all healthy sleep habits, regular daily exercise may be associated with reduced fatigue. While we are unable to make a direct correlation between the two based on this research alone, it is not unreasonable to accept this as good clinical evidence given all the benefits we know of exercise in other aspects of Parkinson's disease. Healthy sleep habits are likely only part of the factors that contribute to sleep and there is a possibility that fatigue and sleep disturbances are reflective of progression of PD itself and more research is needed.

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