

## Sleep in Individuals with Parkinson's Disease with and without Deep Brain Stimulation

### INTRODUCTION

Research has found that a large percentage of individuals with Parkinson's disease (PD) experience various sleep difficulties including insomnia, sleep apnea, restless leg syndrome, and REM sleep disorder.<sup>1,2,3,4,5</sup> There are many causes of sleep disturbances including difficulties related to PD itself as well as the drugs used to treat it.<sup>4</sup> That being said, investigating the quality of sleep is very important for individuals with PD, as there is some evidence that physicians may under-diagnose sleep disorders in PD patients, and it has been shown that lack of sleep can cause additional physical and mental problems which negatively affect one's quality of life.<sup>6</sup>

### OBJECTIVE

The goal of this project was to learn more about sleep in individuals with PD who have and have not undergone **Deep Brain Stimulation of the Subthalamic Nucleus (DBS-STN)**, and to study the relationship between sleep and certain patient variables (e.g., disease duration, time since DBS, and other clinical features).

### METHODS

The participants were recruited from a variety of sources. Some had participated in previous surveys conducted by The Parkinson Alliance; others responded to study announcements in medical clinics around the country, and still others found out about the study through their participation in local PD support groups, The Parkinson Alliance website ([www.parkinsonalliance.org](http://www.parkinsonalliance.org)), or our affiliate website devoted to DBS ([www.dbs-stn.org](http://www.dbs-stn.org)). Participants came from around the United States as well as Canada and the UK. The participants in this report included 87 individuals with PD who underwent DBS and 76 individuals with PD without DBS.

### RESULTS

The summary of the demographic information for this study can be found in Table 1. The average age of PD onset was 46 years for the **DBS group** and 58 years for the **Non-DBS group**. Male and female participants were equally represented for each group and most of the patients were married. The **DBS group** was younger and had an earlier age of onset of PD than the **Non-DBS group**.

**Table 1. Demographics and clinical features of the sample.**

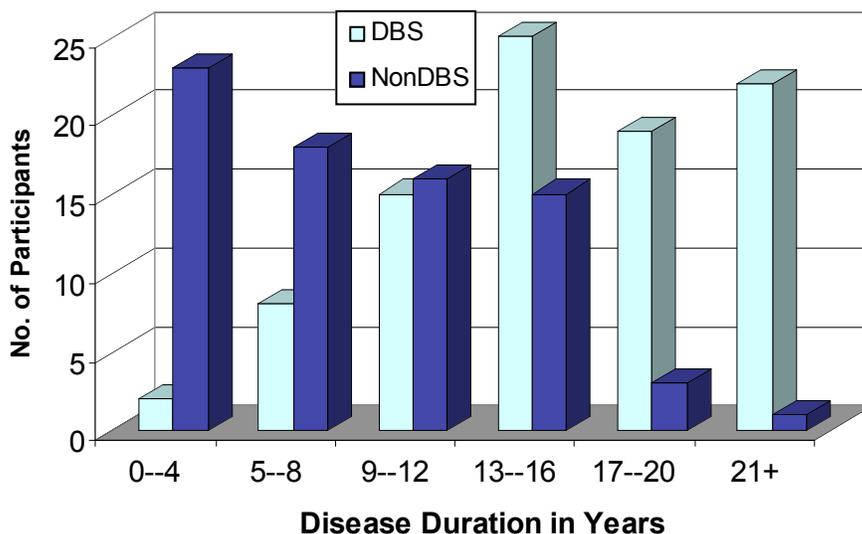
<b>Variable</b>	<b>DBS (n=87)</b>	<b>Non-DBS (n=76)</b>
Mean Age in years *	62	66
Duration of PD in years *	15.9	8.3
Percent Male	52%	53%
Percent Female	48%	47%
Percent Married	73%	71%
Mean Age of PD onset (in years)*	46	58
Average Time since DBS-STN (in years)	3.8	n/a

\* denotes significant differences between the groups

***Duration of PD within the two groups:***

There was a significant difference in duration of PD between the two groups (**DBS>Non-DBS**; see Figure 1). For research purposes it is important to take duration into consideration, which was done for all of the results reported below.

**Figure 1. Disease Duration Categories (in Years) for DBS and Non-DBS groups**



**Sleep Symptoms:**

When the **two groups** were asked if they had a sleep disturbance, the **DBS group** reported fewer problems with sleep than the **Non-DBS group** (see Table 2). We also found that the **DBS group** reported that they slept (on average) longer than those without DBS. There were no differences in persons with

PD (with or without DBS) as it relates to experiencing the different types of sleep disturbances (insomnia, narcolepsy, sleep apnea, restless leg syndrome, or REM sleep disorder).

Many people require medication to help fall asleep or stay asleep. In this study, approximately 34-40% of both groups were taking medication for sleep and the majority of them found that the medications worked (see Table 2).

Another concern with Parkinson’s disease is that people will experience vivid dreams or nightmares. Some people will also have sleeping difficulties that cause them to act out their dreams. A little less than half of each group reported that they experienced vivid dreams or nightmares and 26-32% had acted out their dreams (see Table 2). When individuals experience these types of difficulties they may undergo a sleep study (going into a doctor’s lab while they watch you sleep) for additional evaluation and treatment. It is notable that few individuals in either group had undergone a sleep study.

**Table 2. Self-reported information about the participants’ sleep**

Variable	DBS	Number of people who responded out of 87	Non-DBS	Number of people who responded out of 76
General Sleep disturbance*	39.7%	78	56.7%	67
Hours of sleep w/o waking	5.3 hours	84	4.4 hours	75
Average hours of sleep*	7.1 hours	85	6.3 hours	75
Positive effect of sleep meds	93.3%	30	96.7%	30
Vivid Dreams or Nightmares	46.5%	86	45.9%	74
Acting out dreams	32.5%	83	26.4%	72
Undergone a sleep study	15.3%	85	21.3%	75

\* denotes significant difference

Those that had DBS were also asked to identify to what extent DBS impacted their sleep. About half of the group indicated that they experienced changes and the majority of that group suggested that that they had less sleep disturbance after their DBS (see Table 3).

**Table 3. Percentage of DBS group Reporting change in sleep disturbance after DBS (n=50)**

Variable	Sleep
More disturbance	15.7%
Less disturbance	58.8%
No Change	25.5%

## Summary of Parkinson's Disease Sleep Scale (PDSS):

The PDSS<sup>7</sup> was developed to specifically measure issues related to sleep in persons with PD. The PDSS scores confirmed that both groups were experiencing difficulties with their sleep. However, there were some notable differences between the groups. Specific responses to the questionnaire can be reviewed in Table 4, which is located at the end of this report.

The results from the PDSS can be summarized as follows: the **DBS group** reported better quality of sleep when compared to the **Non-DBS group**. The **DBS group** also reported that it was easier to fall asleep than the **Non-DBS group**. The **DBS group** was better able to stay asleep and reported fewer distressing hallucinations at night as compared to the **Non-DBS group**. The **DBS group** reported less painful muscle cramps in their arms and legs while sleeping at night. The **DBS group** also had less frequency of waking up early in the morning due to painful posturing of arms and legs, which can frequently occur with PD. Lastly, the **DBS group** reported less frequency of tremor upon waking than the **Non-DBS group** (see Table 4).

Both groups reported an equal amount of experiencing restlessness of legs or arms at night or in the evening that caused sleeping difficulties. Additionally, we did not find any differences between groups in regard to fidgeting in bed, suffering from distressing dreams at night, getting up to go to the bathroom, having incontinence of urine because of the inability to move due to "off" symptoms, or experiencing numbness or tingling of one's arms or legs which wake the person from sleep at night. Additionally, the groups were not different in regards to feeling tired and sleepy after waking in the morning and unexpectedly falling asleep during the day (see Table 4).

When looking at the relationship between the *duration of PD* for **all of the participants** in this study (as a whole) and specific issues related to sleep disturbance, there were significant findings. Specifically, the longer the participants of this study have had PD the worse the overall quality of sleep. The longer participants have had PD the greater difficulty they had falling asleep, the greater difficulty they had staying sleep, the more they experience numbness or tingling of their arms or legs which wake them from sleep at night, the more likely they were to wake up early in the morning with painful posturing of arms or legs, and the more likely they wake up experiencing tremor.

## DISCUSSION

- Sleep disturbance is quite evident in the PD population and was confirmed in this study, for both the **DBS** and **Non-DBS groups**.
- General estimates suggest that approximately 20-47% of PWP will have sleep disturbances including insomnia, restless legs, vivid nightmares, and acting out dreams.<sup>1</sup> We found that the participants in this study experience similar amounts of sleep disturbances as commonly seen in the general PD population.
- We looked at various factors that can affect sleep (e.g. consumption of alcohol and caffeine) and did not find that any of these factors significantly affected sleep for either group.
- Consistent with previous research, DBS-STN had a significant and positive impact on the quality of nighttime sleep, and this can likely be attributed to the fact that this surgical procedure minimizes, if not eliminates, some of the motor symptoms that are known to cause fragmented sleep.<sup>9</sup> This research reflects that the **Non-DBS group** reported greater incidence of sleep disturbance across many symptoms of sleep dysfunction as compared to the **DBS group**. Thus, these results suggest the sleep differences between these two groups can be, at least in part, attributed to impact that DBS has on physical symptoms. Additionally, it is possible that the improvement of sleep can be attributed, in part, to the decreasing of Parkinson-related medication following DBS-STN, as some of these medications can have a side effect of sleep disturbance.<sup>1</sup>  
<sup>10</sup> For example, it is notable that the **DBS group** reported less hallucinations than the **non-DBS group** possibly due to medication effects. Typically after DBS there is a reduction in the PD

medication needed and research has shown a higher likelihood of hallucinations due to the PD medications.<sup>1</sup>

- The beneficial effects of DBS-STN on sleep are encouraging for many reasons. For example, improving sleep is likely linked to improving quality of life, and the typical reduction of Parkinson-related medication following DBS-STN may decrease daytime sleepiness and reduce nighttime hallucinations, which are side effects of many PD medications.<sup>1, 10</sup>
- Although it is encouraging that those **with DBS** reported longer amounts of sleep and less sleep disturbance after surgery and that the **DBS group** was generally sleeping better than the **Non-DBS group**, it is discouraging that both groups reported more sleep disturbances as compared to a general adult population; 17.4% of the general population reported having sleep disturbance<sup>8</sup> as compared to the significantly higher percentages of reported sleep disturbances found in the participants in this study. This finding suggests that more research needs to be done in regards to identifying causes of and better treatment for sleep disturbances in persons with PD.

## UPCOMING REPORTS

1. Summary of the results for the project entitled: **The Relationship between Sleep and Emotional Well-being in Individuals with Parkinson's Disease with and without Deep Brain Stimulation.**

## ACKNOWLEDGEMENTS

As we complete our fourth DBS-STN patient survey, which will be divided into three reports (anxiety and depression; sleep disturbance; and the relationship between sleep and emotional disturbance in PD patients), I am fortunate to be working with three People with Parkinson's (PWPs), Richard Kramer, who also had DBS, and John Wherry and Ram Ramchandran. Their input and data analysis is very important to our work. We also have two Neuropsychologists who analyze the data and add their professional skills to our work, including Dr. Jeffrey C. Wertheimer, staff Neuropsychologist for Brooks Rehabilitation Hospital, and Dr. Julie Smith, staff Neuropsychologist for Henry Ford Hospital. Additionally, I want to thank Valentina Trepatschko, a staff member of The Parkinson Alliance, for all of her diligence and assistance in data collection and organization, and I want to acknowledge the ongoing dedication and tenacity of Carol Walton, Executive Director for The Parkinson Alliance, as she phoned, wrote, and visited a multitude of DBS facilities across the country to recruit participants for this research project. Furthermore, I would like to thank the rest of the Parkinson Alliance staff for their contributions.

I am very grateful to the people who took time to fill out the survey and to the many carers without whom our lives would not be as meaningful.

Margaret Tuchman,  
President,  
The Parkinson Alliance

**Table 4: Parkinson’s Disease Sleep Scale: Differences between DBS and Non-DBS participants**

Questions related to sleep	Non-DBS (n=76)	DBS (n=83)
<b>* Overall Quality of your nights sleep:</b>		
Awful	13%	15%
Fair	75%	49%
Good/excellent	12%	36%
<b>* Do you have any difficulty falling asleep at night?</b>		
Almost always to always	15%	8%
Sometimes	38%	34%
Almost never to never	47%	58%
<b>* Do you have trouble staying asleep?</b>		
Almost always to always	49%	31%
Sometimes	34%	37%
Almost never to never	17%	32%
<b>Do you have restlessness of legs or arms at night or in the evening causing disruption of sleep?</b>		
Almost always to always	16%	15%
Sometimes	28%	22%
Almost never to never	56%	63%
<b>Do you fidget in bed?</b>		
Almost always to always	21%	18%
Sometimes	34%	28%
Almost never to never	45%	54%
<b>Do you suffer from distressing dreams at night?</b>		
Almost always to always	9%	9%
Sometimes	33%	35%
Almost never to never	58%	57%
<b>* Do you suffer from distressing hallucinations at night (seeing or hearing things that you are told do not exist)?</b>		
Almost always to always	9%	2%
Sometimes	15%	7%
Almost never to never	76%	91%

**Table 4: Parkinson’s Disease Sleep Scale: Differences between DBS and Non-DBS participants cont’d**

Questions related to sleep	Non-DBS (n=76)	DBS (n=83)
<b>Do you get up at night to pass urine?</b>		
Almost always to always	67%	54%
Sometimes	24%	27%
Almost never to never	9%	19%
<b>Do you have incontinence of urine because you are unable to move due to “off” symptoms?</b>		
Almost always to always	8%	6%
Sometimes	12%	11%
Almost never to never	80%	83%
<b>Do you experience numbness or tingling of your arms or legs which wake you from sleep at night?</b>		
Almost always to always	9%	10%
Sometimes	26%	15%
Almost never to never	65%	75%
<b>* Do you have painful muscle cramps in your arms or legs whilst sleeping at night?</b>		
Almost always to always	22%	12%
Sometimes	34%	26%
Almost never to never	44%	62%
<b>* Do you wake early in the morning with painful posturing of arms or legs?</b>		
Almost always to always	24%	17%
Sometimes	32%	15%
Almost never to never	44%	68%
<b>* On waking do you experience tremor?</b>		
Almost always to always	22%	11%
Sometimes	22%	10%
Almost never to never	56%	79%
<b>Do you feel tired and sleepy after waking in the morning?</b>		
Almost always to always	40%	30%
Sometimes	40%	41%
Almost never to never	20%	29%

**Table 4: Parkinson’s Disease Sleep Scale: Differences between DBS and Non-DBS participants cont’d**

Questions related to sleep	Non-DBS (n=76)	DBS (n=83)
<b>Have you unexpectedly fallen asleep during the day?</b>		
Almost always to always	33%	31%
Sometimes	32%	32%
Almost never to never	35%	37%

\* Denotes significance between groups

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