

# Comparing Quality of Life in Parkinson's Disease Patients with and without Deep Brain Stimulation

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## INTRODUCTION

Understanding the impact deep brain stimulation (DBS) has on the quality of life (QoL) in patients with Parkinson's disease (PD) is of on-going need. The effectiveness of DBS for the treatment of motor symptoms in PD is well documented, but the long-term impact of DBS on the multi-faceted components of quality of life is less extensively studied. In addition, few studies have compared QoL in PD patients with and without DBS. Moreover, there are several symptoms to consider when assessing QoL in patients with PD. Beyond the motor symptoms exist several disturbing and potentially debilitating non-motor symptoms that patients with PD might experience (e.g., emotional disturbance, sleep disturbance, speech disruption, etc.), and some studies suggested that such non-motor symptoms have as much of an impact, if not more so, on quality of life than motor symptoms (Troster et al., 2003).

## OBJECTIVES

- To expand upon the preliminary findings (Wertheimer et al., 2004) by comparing QoL and symptoms of depression in Parkinson's disease patients with and without deep brain stimulation of the subthalamic nucleus (DBS-STN).
- To examine how certain patient and clinical variables (e.g., age, gender, disease duration, time since DBS surgery, and other features) relate to one's report of quality of life and depression.
- To continue establishing a large, representative cohort of DBS-STN patients who can be surveyed at regular intervals (e.g., every 6-12 months) so that change across time in multiple areas (motor symptoms, emotional status, quality of life and health, etc.), can be better understood.

Although these research methods are more *descriptive* and *exploratory* than truly *experimental*, they nonetheless can contribute to the scientific understanding of how PD patients experience, cope with, and benefit from DBS-STN. In addition, this study is one of the few that have compared QoL in PD patients with and without DBS.

## METHODS

- A mail-survey/questionnaire methodology was used. The participants were recruited from a variety of sources. Some had completed previous surveys conducted by The Parkinson Alliance (Tuchman et al., 2003; Tuchman, et al., 2004; Wertheimer, et al., 2004). Other participants learned about the study by visiting our website ([WWW.DBS-STN.ORG](http://WWW.DBS-STN.ORG)), 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.
- In total, 113 PD patients who underwent DBS of the subthalamic nucleus and a comparison group of 72 PD patients who did not have surgery were included in this study.
- Each participant completed a PD/DBS-specific measure of quality of life (Kuehler et al., 2003), the Beck Depression Inventory-II (BDI-II; Beck, 1996), and a supplemental questionnaire assessing demographics and other clinical characteristics of the sample.

## RESULTS

TABLE 1 summarizes the demographic and clinical information about the sample. We have collected data from a large, representative group of PD patients spanning a broad range of age and clinical features.

**Table 1: Summary of the Demographic and Basic Clinical Variables**

Group	DBS-STN		Non-DBS	
Variable	Mean (SD) or Percentage	Range	Mean (SD) or Percentage	Range
<b>Age</b>	62 years (9.7 yrs)	32-82 yrs	61 yrs (10.9 yrs)	30-95 yrs
<b>Gender</b>	62% Male		50% Male	
<b>Marital Status</b>	79% Married		80% Married	
<b>Age of PD Onset</b>	48 yrs (10 yrs)	21-67 yrs	54 yrs (11.2 yrs)	29-83 yrs
<b>Duration of PD</b>	15 yrs (4.7 yrs)	4-27 yrs	8 yrs (5.8 yrs)	<1-28 yrs
<b>Time since DBS-STN</b>	37 months (17.7 mths)	5-103 mths		
<b>Percent Working</b>	76% Not Working		72% Not Working	
<b>Percent Driving</b>	41% Not Driving		24% Not Driving	

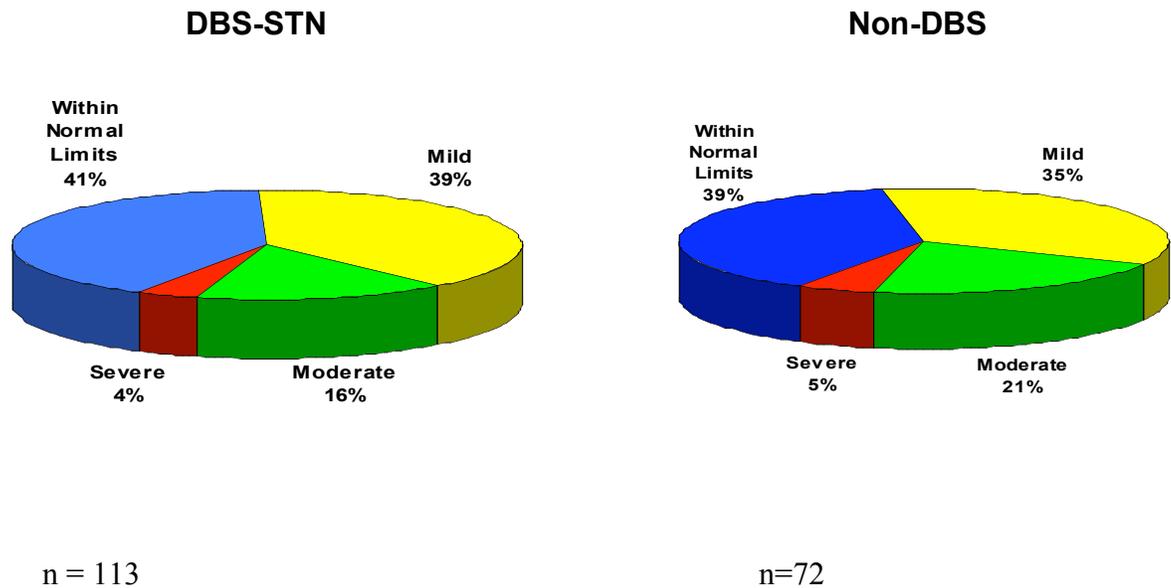
As shown in the table above, the average age of the DBS and non-DBS groups did not differ significantly. The groups were well-matched in terms of gender and marital status. The average duration of PD in the DBS group was nearly twice as many years (DBS=15.7 years,

non-DBS=8.1 years). In addition, the non-DBS participants had a significantly later age of PD onset compared to the DBS group. Although similar proportions of DBS and non-DBS participants were not currently working, significantly more DBS participants were not driving an automobile.

### SUMMARY OF BDI-II DATA

**Graph 1**

#### Severity of Depression: Beck Depression Inventory-II



- There were no significant differences between the two groups on the BDI-II even after controlling for disease duration.
- The amount of individuals reporting a history of having been diagnosed with depression was comparable between groups (DBS=40%; non-DBS=46%; n=113 and 72, respectively).
- Significantly more non-DBS participants reported depression that existed prior to being diagnosed with PD (DBS=20%, non-DBS=51%; n=54 and 41, respectively).
- A smaller proportion of DBS patients were taking antidepressant medications (DBS=40%, non-DBS=45%).
- Of those participants taking an antidepressant, DBS participants reported that they felt antidepressants were less effective than the non-DBS group.

## SUMMARY OF QOL DATA

**Table 2. Descriptive Statistics for the QoL Questionnaire.**

Group	DBS		Non-DBS	
Variable	Mean (SD)	Range	Mean (SD)	Range
<b>QoL – Overall Life Satisfaction</b>	7.19 (5.11)	-7 to 20	8.09 (4.78)	-6.38 to 20
<b>QoL – Health Satisfaction</b>	4.94 (6.24)	-9.75 to 18	4.21 (6.83)	-12 to 19
<b>QoL – Movement Disorders Satisfaction</b>	3.76 (5.32)	-9.42 to 17.17	4.76 (6.14)	-9.83 to 20
<b>QoL – DBS Overall Satisfaction</b>	10.44 (5.04)	-.6 to 20	N/A	N/A

- Essentially equivalent levels of overall satisfaction with health, quality of life, and movement disorder symptoms were observed between the two groups with one exception: speech problems.
- Irrespective of disease duration, a statistically significant difference between the two groups emerged on self-reported problems with articulation and fluency of speech (Cohen’s d effect size = .77).
- The relationship between disease duration and satisfaction with overall severity of the movement disorder was correlated in the non-DBS group, but not the DBS group.
- Depressive symptoms were highly predictive of poor satisfaction with multiple scales of health, social, and movement disorder-related QoL and high rates of self-reported depression were evidenced in both groups.

## DISCUSSION

- These results contribute uniquely to an emerging body of research whose aim is to document and understand clinically relevant QoL variables in patients with PD who have or have not undergone DBS.

- DBS and non-DBS groups do not differ from one another in terms of overall quality of life or depressive symptoms. This suggests, as others have shown (Takeshita, et al., 2005), that DBS does not appear to lead to depression or worsening of QoL.
- This study continues to highlight the importance of assessing and treating emotional status in patients with Parkinson's disease, with and without DBS. Depression, in particular, plays a major role in one's overall report of quality of life.
- Our findings indicate, not unexpectedly, that as the duration of PD increases in the non-DBS group, severity of movement disorder increases. We did not find this in the DBS group, a finding that supports the view that DBS disrupts the typical relationship between duration of PD and severity of movement disorder. Although indirect and based solely on self-report data, these findings are consistent with the finding of other controlled studies that support the efficacy of DBS for the improvement of movement disorder symptoms.
- As other studies have shown (Santens et al., 2003; Thobois et al., 2002), this study suggests that problems with speech fluency and articulation are of particular concern in the context of DBS. Consequently, more research is needed to more fully understand the speech changes that occur after DBS.
- It must be remembered that this research is descriptive and exploratory, not experimental. Therefore, our findings must be considered in the context of other research conducted in this area and within the limits of the methodology used. For example, in use of self-report methods, retrospective memory for events can be a caveat. In this study significantly more non-DBS participants reported depression that existed prior to being diagnosed with PD than the DBS group. This is an intriguing finding, but one must consider that the average time since the diagnosis of PD for the non-DBS group was 8 years and the DBS group's average was approximately 16 years following diagnosis. Consequently, questions about the reliability of self-report for "feelings" occurring in the distant past may be raised, for both groups.

### **FUTURE DIRECTIONS**

- Our future work will include a longitudinal study of this cohort of DBS and non-DBS patients. This research will provide much needed information about the effect of DBS over time, including both the benefits and risks as experienced and reported by the patient.
- Our team has learned valuable information about quality of life research and, after reviewing the available questionnaires used to assess QoL in PD, we believe that better instruments can be developed that will be comprehensive, standardized, and clinically useful. As such, The Parkinson Alliance has developed the "Parkinson Alliance Quality of Life Survey" (PAQLS). A pilot study is currently underway, and future studies will soon follow.

- Investigations of non-motor symptoms of Parkinson's disease, particularly after DBS intervention, continue to be warranted. We will be investigating the role of sleep disturbance and anxiety in our succeeding research projects.

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I am very grateful to the people who took time to fill out the survey and to the many care-partners who daily hold the lives of the PD patients together.

Margaret Tuchman,  
President,  
The Parkinson Alliance

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