

# Caregivers' Impression About the Effect of Subthalamic Nucleus Deep Brain Stimulation in the Treatment of Parkinson's Disease

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## ABSTRACT

**AIM:** To determine caregivers' impressions of the impact of STN-DBS on motor and non-motor symptoms of Parkinson's disease (PD) in patients who underwent subthalamic nucleus deep brain stimulation (STN-DBS), evaluate the relationship of these changes with disease characteristics, and examine their contribution to the daily lives of patients.

**MATERIAL and METHODS:** The caregivers of patients who underwent STN-DBS were interviewed over the telephone. All telephone interviews were recorded, and changes in the motor and non-motor symptoms of the patients after STN-DBS were evaluated with a standardized questionnaire.

**RESULTS:** Of the 173 patients with PD who underwent STN-DBS between 2005 and 2015, 62 who could be contacted by telephone were enrolled in the study. The mean age of the patients was  $59.71 \pm 9.78$  years (range: 33-77 years). The mean disease duration was  $15.62 \pm 8.66$  years (Range: 4-50 years). STN-DBS was performed on average  $3.88 \pm 2.6$  years earlier (range: 1-11 years). According to the caregivers of the patients, there was a reduction in "off" periods in 79% of the patients, tremor in 58.1%, dyskinesia in 59.6%, depression in 46.8%, pain symptoms in 41.9%, and improvement in sleep problems in 43.6% after STN-DBS. Moreover, 80.6% of the patients reported an improvement in their daily life activities after STN-DBS.

**CONCLUSION:** From the caregivers' perspective, there was an improvement in the non-motor symptoms as well as the motor symptoms of patients with PD after STN-DBS, and this had a positive effect on the activities of daily lives in the majority of patients. Telephone interviews can be considered as an alternative method in the follow-up of patients with PD, especially when they cannot be assessed face-to-face.

**KEYWORDS:** Parkinson's Disease, DBS, Caregiver impression

## INTRODUCTION

Parkinson's disease (PD) has a complex clinical presentation with motor and non-motor features observed both in the early and late stages of the disease. Therefore,

symptomatic treatment strategies are individualized based on the age of onset, existing motor and/or non-motor symptoms, and treatment-induced complications (7). Since medical treatment options are effective in alleviating the motor symptoms of PD in a limited period, and motor complications,

such as dyskinesia and motor fluctuations occur as the disease progresses, deep brain stimulation (DBS) is considered as a favorable treatment option in patients who are responsive to levodopa but have insufficiently controlled symptoms by medication or experience medication-related complications, e.g., dyskinesia and motor fluctuations (5,15).

DBS is considered to act through the delivery of an electrical current in a selected target of the brain leading to several mechanisms of action, such as depolarization blocks, activation of axons related to inhibitory neurons, desynchronizing tremorogenic pacemakers, or disruption of the network. However, the exact mechanism of action remains unclear (7,14).

One of the most common targets in the symptomatic treatment of PD is reported as subthalamic nucleus (STN -DBS, which has been found to be effective in improving cardinal motor symptoms, such as bradykinesia, rigidity, tremor, and postural instability, and prolongs the “on” time, leading to an improvement in the quality of life (4,13). In addition to these well-established benefits of STN-DBS on motor symptoms and medication-induced complications, this treatment option has also been shown to be effective in some non-motor symptoms of PD (3).

Since both motor and non-motor symptoms of PD and related complications are the main reasons of disability, as well as the familial and/or social burden for the caregivers of the patients, which are considered to improve with STN-DBS, it may be crucial to investigate the impact of STN-DBS on patients' well-being from the caregivers' perspective (3,12). However, there are a limited number of studies assessing caregivers' impression of STN-DBS (9,11,12). Therefore, we aimed to investigate possible changes in the motor and non-motor symptoms of patients with PD after STN-DBS from the perspective of their caregivers.

## ■ MATERIALS and METHODS

This study was held at the neurology and neurosurgery departments of Ankara University School of Medicine. We aimed to enroll patients with a diagnosis of PD, who underwent bilateral STN-DBS in Ankara University School of Medicine between 2005 and 2015.

Patients whose phone numbers could be obtained were contacted via telephone (n=62) by a neurology specialist. All the telephone interviews were carried out with the adequate understanding and consent of the patients involved, and the verbal consent and approval of the participants was recorded.

During the telephone interviews, a standardized questionnaire was used to detect possible changes in the patients' motor and non-motor symptoms after STN-DBS. The questionnaire consisted of three main items evaluating the motor and non-motor symptoms and the effects of these symptoms on the daily lives of the patients with PD (Table I). This questionnaire was used in a previous study, and all the questions were found to be valid, reliable, and consistent, based on the Cronbach alpha value of 0.753 (16). The participants' demographic data,

including age and sex, duration of PD, and time elapsed since STN-DBS were recorded.

All the data were organized and analyzed using the Statistical Package for the Social Sciences (SPSS) for Windows, version 20. Descriptive statistics (mean, standard deviation, range, and 95% confidence interval) were obtained for each variable as required. p values of <0.05 were considered to indicate statistical significance.

## ■ RESULTS

Our medical record review revealed that 173 patients with PD underwent STN-DBS between 2005 and 2015. Due to the absence of telephone number information of 87 patients in medical records, we were only able to use the phone numbers belonging to the remaining 86 patients; however, it was determined that the phone number provided was not valid in 19 patients, three patients had died, and for two patients whose relatives answered the phone were not aware of the current status of the patients. Thus, 62 patients were included in the final analysis. Twenty-one (33.9%) patients were women and 41 (66.1%) were men. Data about the patients were obtained from the caregivers of the patients who were first-degree relatives in 61 (98.4%) patients and employed caregivers in one (1.6%) patient.

The mean age of the patients was  $59.7 \pm 9.78$  years (range: 33-77 years), and the mean duration of PD was  $15.62 \pm 8.66$  years (range: 5-50 years). The mean time since STN-DBS was  $3.88 \pm 2.6$  years (range: 1-11 years).

Changes in the motor and non-motor symptoms of the patients with PD after STN-DBS are summarized in Table II. The duration of OFF 'off' periods was reported to be better after STN-DBS in 49 patients (79%). Forty-five patients reported to have dyskinesia and 37 (59.6%) stated that they were better after STN-DBS. Similarly, among all the patients, 36 (58.1%) reported that they were better in terms of tremors after the procedure. Fifty-eight of the 62 patients had the complaint of gait disorder and ataxia, and 37 (59.6%) reported that they felt better after STN-DBS. When we assessed the non-motor items, depression was found to be the most common non-motor symptom. Fifty-two (83.9%) patients reported that they had depression, while 10 (16.1%) reported that they had no depression prior to STN-DBS. Of the 62 patients, 29 (46.8%) were found to be better in terms of depression symptoms after STN-DBS. The second common non-motor complaint was sleep problems. When we evaluated the responses of the participants, 48 (77.4%) reported that they had sleep problems, while 14 (22.6%) had no such complaint prior to STN-DBS. Twenty-seven (43.6%) of the 62 patients reported that they felt better after STN-DBS. Similarly, 26 (41.9%) of the 62 patients stated that they were better in terms of pain after the procedure. Urinary incontinence was the least frequent complaint reported by 25 patients, of whom nine (14.6%) stated that there was an improvement in this complaint after STN-DBS. Concerning the overall effect of the disease, 50 (80.6%) patients considered that their daily lives were better after STN-DBS (Table II).

**Table I:** Motor and Non-Motor Symptom Questionnaire

Assessment of motor and non-motor symptoms	Better	Same	Worse	I don't know	I had no such complaint
<b>Motor symptoms</b>					
Has there been any change in the "off" periods?					
Has there been any change in involuntary movements (jerks, flings-not tremor, etc.) during daytime?					
Has there been any change in tremors?					
Has there been any change in gait disorder and ataxia?					
<b>Non-motor symptoms</b>					
Has there been any change in pain?					
Has there been any change in sleep disturbance?					
Has there been any change in mood (happiness, sadness, etc.)?					
Has there been any change in urinary incontinence?					
<b>Daily life effects</b>					
Has there been any change in the activities of daily life (eating, dressing, having a bath, etc.)?					
<b>TOTAL</b>					

**Table II:** Changes in the Motor and Non-Motor Symptoms of Patients with PD after STN-DBS

	Duration of "off" periods n (%)	Dyskinesia n (%)	Tremor n (%)	Gait disorder and ataxia n (%)	Pain n (%)	Sleep problems n (%)	Depression n (%)	Urinary incontinence n (%)	Daily life n (%)
Better	49 (79.0)	37 (59.6)	36 (58.1)	37 (59.6)	26 (41.9)	27 (43.6)	29 (46.8)	9 (14.6)	50 (80.6)
Same	6 (9.7)	4 (6.5)	7 (11.3)	11 (17.8)	4 (6.5)	17 (27.4)	18 (29.0)	10 (16.1)	8 (12.9)
Worse	7 (11.3)	4 (6.5)	1 (1.6)	10 (16.1)	1 (1.6)	2 (3.2)	3 (4.9)	2 (3.2)	3 (4.9)
I don't know	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	2 (3.2)	2 (3.2)	2 (3.2)	4 (6.5)	1 (1.6)
I have no such complaint	0 (0.0)	17 (27.4)	18 (29.0)	4 (6.5)	29 (46.8)	14 (22.6)	10 (16.1)	37 (59.6)	0 (0.0)

**PD:** Parkinson's disease, **STN-DBS:** Subthalamic nucleus deep brain stimulation.

**DISCUSSION**

STN-DBS is a well-established treatment option in PD, which probably has the advantages of promoting faster non-hypersynchronous activity in basal ganglia that leads to clinical improvement and reducing the need for medications, as well as the burden on caregivers via reducing the stress on patients' family life and social environment (9-12,16). However, there are only a limited number of reports on caregivers' impression of PD patients that have undergone STN-DBS treatment (10).

Supporting the beneficial effects of STN-DBS on this theoretical basis, we aimed to assess the effects of STN-DBS on the motor and non-motor symptoms and complications of the disease, as well as the impact of the procedure on the

daily activities of the patients from the caregivers' perspective using telephone interviews. In the literature, there is only one study using telephone interviews in patients with PD, and in that study, Chahine et al. evaluated the effects of STN-DBS on restless legs syndrome and sleep-related measures in this patient population (2). Therefore, our study seems to be the first to assess the effects of STN-DBS on the overall symptomatology of the disease and explore its effects on the daily life activities of the patients.

The majority of our participants reported a marked clinical improvement in the motor symptoms and complications of PD after STN-DBS in relation to "off" periods, dyskinesia, and tremor, similar to current literature knowledge (Table II) (15).

In addition to motor symptom improvement, Jafari et al. also demonstrated a statistically significant decrease in the non-motor symptoms of PD, including sleep problems, urinary problems, and pain complaints in the one-year-follow-up visit of the patients who underwent STN-DBS when compared with the baseline evaluations ( $p < 0.05$ ). Although there was a decline in depressed mood, it was not found to be statistically significant ( $p = 0.363$ ) (6). Similarly, the multicenter European study (EuroInf) reported that the STN-DBS procedure significantly improved non-motor outcomes, including sleep and mood and led to an overall wellness in the quality of life of patients (3).

Similar to the literature, the majority of our patients reported a sufficient improvement in their non-motor symptoms, including pain, sleep disturbance, and depressive mood after STN-DBS, as well as motor symptom improvement. In parallel to this increased well-being in relation to motor and non-motor symptoms, 80.6% of the patients stated a marked improvement in their activities of daily life.

In this study, 59.6% of our patients had no urinary complaint before STN-DBS, and the responses of the remainder patients with bladder problems before STN-DBS to the question evaluating bladder control did not differ statistically (Table II). Therefore, the lack of information concerning the effects of STN-DBS on bladder control can be considered as a limitation of our study and needs further assessment.

In addition to the above-mentioned literature findings revealing the positive effects of STN-DBS on the motor and non-motor symptoms of PD, which are challenging for patients themselves, Leiknes et al. showed that these symptoms might also affect the patients' family and social environment, leading to negative consequences for the quality of life of the patients' caregivers (8). Based on the distress and burden of PD symptomatology which are shown to improve with STN-DBS in the majority of patients, recent studies have focused on the effects of STN-DBS on the overall well-being of patients and, to some extent, their caregivers. However, the majority of these studies reflect the caregivers' perception of STN-DBS on their self-well-being rather than that of the patients. Thus, current knowledge concerning the effects of STN-DBS on the motor and non-motor disabling symptoms of patients with PD from the caregivers' perspective still seems to be insufficient (1,2,8-12,16).

Our study investigated the caregivers' impression about the efficacy and effects of STN-DBS on the motor and non-motor symptoms of the patients with PD and explored the effects of this procedure on the daily life activities of the patients via telephone interviews. According to our literature review, this is the first study to conduct telephone interviews with the caregivers of patients with PD to assess the effects of STN-DBS on the overall symptomatology and complications of the disease and one of the few studies reflecting caregivers' own opinions about the efficacy of STN-DBS in relieving the symptoms and complications of their patients.

Considering the current pandemic conditions that have affected the health system across the world, the use of phone

interviews has become an important method for patient evaluations. However, the methodology itself can be considered as a limitation of our study, which resulted in a decrease in the number of patients who were included in the final analysis due to the lack of valid phone number information. As a result, we were not able to contact the overall study population of 173 PD patients that had undergone STN-DBS.

## ■ CONCLUSION

Since our results demonstrated that STN-DBS alleviated many non-motor symptoms, which can be as troublesome as motor symptoms, and also improved complications, leading to a marked decline in the burden of PD on the quality of life of patients from their caregivers' point of view, which is consistent with previous studies using face-to-face assessments or retrospective analyses. Telephone interviews can be considered as an alternative method in the follow-up of patients with PD, especially when they cannot be assessed face-to-face due to various social and other relevant factors.

### AUTHORSHIP CONTRIBUTION

Study conception and design: MCA, AS

Data collection: YD, ST

Analysis and interpretation of results: YD, ST, MCA

Draft manuscript preparation: YD, ST

Critical revision of the article: MCA, AS

Other (study supervision, fundings, materials, etc...): MCA, AS

All authors (YD, ST, AS, MCA) reviewed the results and approved the final version of the manuscript.

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