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Expectations and Level of Satisfaction of the Patient with Parkinson's Disease Undergoing Deep Brain Stimulation Surgery at the National Institute of Neurology and Neurosurgery

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Abstract

Background: Deep brain stimulation (DBS) is an established treatment for patients with advanced Parkinson's disease (PD). Reports show continued patient satisfaction after surgery despite not maintaining clinical improvement as measured by evolution scales. **Objectives:** The present study sought to explore expectations and level of satisfaction in patients after DBS surgery with a semi-structured questionnaire and subsequent correlation with functional scales, Quality of Life (QoL), and motor and non-motor symptoms. **Methods:** We performed descriptive statistics to represent demographic data, Wilcoxon rank tests to determine significant differences, and Spearman correlation between the applied scales. **Results:** We evaluated 20 patients with a history of DBS surgery. 45% were female, with a mean age of 55.7 ± 14.15 years, a mean disease duration of 13.42 ± 8.3 years, and a mean time after surgery of 3.18 ± 1.86 years. Patients reported surgery meeting expectations in 85.5% and continued satisfaction in 92%. These two variables showed a significant correlation. **Conclusions:** This sample of patients remained satisfied after DBS surgery, although we found no differences in motor and non-motor clinimetric scales. Further studies are needed to confirm the importance of assessing quality of life in patients with DBS.

Keywords

Parkinson's Disease, Quality of Life, Deep Brain Stimulation, Patient Satisfaction

1. Background

Parkinson's disease (PD) is the second most common neurodegenerative disorder and the most common movement disorder, characterized by neuronal loss in the substantia nigra, resulting in striatal dopamine deficiency [1] [2]. PD has a worldwide prevalence of 3% of the population over 65 years of age [1] [3]. Recently it has become one of the leading causes of disability [4]. As the population ages, a dramatic increase in the prevalence of PD is expected, doubling in the next two decades, as aging is the main associated risk factor [5].

We can divide PD into two large stages, early and advanced, facilitating the study and therapeutic approach to the disease [1]. Within the available treatments for PD, there is no curative or disease-modifying treatment [6]. When strategies administered in the early stages are not controlling the motor and no motor complications, we should always consider alternatives, especially for the advanced stage: infusion device-assisted interventions such as continuous subcutaneous apomorphine, levodopa-carbidopa intestinal gel, and deep brain stimulation (DBS) [7].

DBS is a neurosurgical procedure intervening brain structures through implanted electrodes, allowing circuit-based neuromodulation [8]. Currently accepted targets include the globus pallidus internus (GPi) and the subthalamic nucleus (STN) [9]. DBS has demonstrated efficacy in reducing dyskinesias, off-time, motor function and improving activities of daily living [10]. In contrast, side effects such as ocular aperture apraxia, refractory dyskinesia, dystonia, dysarthria, and neuropsychiatric symptoms may occur after neurostimulation [11] [12]. There is plenty of high-quality evidence about the benefits of treatments administered at these stages.

Surveillance of the Motor and not motor manifestations of PD play a critical role in evaluating outcomes and patient expectations of treatment benefits. Assessing the expectations of DBS patients is becoming increasingly popular. However, there are few studies on this topic, especially with long-term follow-up. Patients dissatisfied with DBS may be more reluctant to participate in procedural plans and suffer adverse outcomes. However, greater satisfaction can empower and engage patients, improving outcomes. Understanding the patient's expectations is essential, especially for formulating guidelines and processes to evaluate the results [13].

2. Material and Methods

2.1. Patients

Patients with PD who attended the Movement Disorders clinic at the National Institute of Neurology and Neurosurgery (INNN) from 2011 to 2020 who underwent DBS. Patients who agreed to participate in study signed informed consent. Patients with PD > 18 years of age who underwent DBS from 2011 to 2020 were included. We excluded PD patients with major cognitive impairment or various comorbidities and patients who did not comply with a period of at least

one year between surgery and the follow-up visit.

All diagnoses were performed by a neurologist with expertise in PD, following the UKPDSBB clinical diagnostic criteria. The number and recruitment of patients was for the convenience of the doctors due to the low number of patients with surgery. We administered several questionnaires before DBS surgery one year and after it. The scales applied were MDS-NMSS [14], MDS-UPDRS [15], PDQ-8 [16], and the MoCA test [17]. Additionally, we added an epidemiological data questionnaire, clinical and demographic data regarding gender, age, current comorbidities, age at clinical onset, duration of disease, average time with DBS, antiparkinsonian treatment, Levodopa Equivalent Dose (LED), were collected. And then evaluated satisfaction one year after the DBS surgery with a semi-structured questionnaire consisting of 3 multiple-choice questions with the options from 0 to 100% and 6 "yes" or "no" answered questions.

The local ethics committee approved the protocol (No. 80/19) under the declaration of Helsinki.

2.2. Statistical Analysis

We performed statistical analyses with the statistical package for the social sciences (SPSS) 17th version. We determined the distribution of frequencies and measures of central tendency of the population collected. For the bivariate analysis, we started with the Shapiro-Wilk test to define the normality of the data. Subsequently, we performed a bivariate analysis with t-tests for repeated measurements or their nonparametric equivalent for numerical variables and the McNemar test for nominal variables.

3. Results

Eighty-seven patients with PD underwent DBS surgery during the study period, 47 complied with the one year between the DBS surgery and the follow-up visit, and only 20 fulfilled the selection criteria. Nine were women (45%), with a mean age of 55.7 ± 14.15 years, a mean duration of the disease of 13.42 ± 8.3 years, a mean disease duration to surgery 10.37 ± 8.4 years, and an average time with the DBS of 3.18 ± 1.86 years. DBS was placed in the subthalamic nucleus (STN) bilaterally in all cases, mean H&Y scale of 2.41 ± 1.01.

Regarding drug treatment, patients received a mean LED of 684.5 ± 466 mg/day, 20% dopamine agonist use. Among the comorbidities identified in the patients, type 2 diabetes was present in 20%, 10% had systemic arterial hypertension, and 15% had dyslipidemia. Other sociodemographic characteristics report a mean education duration of 10.37 ± 8.4 years and a family history of PD 25%.

Regarding results of the MDS-UPDRS, NMSS, PDQ-8, and MoCA scales, we obtained the score averages of each scale in the preoperative evaluation and at one year of follow-up. We show differences between both assessments in **Table 1**.

Finally, we obtained the results of the semi-structured patient satisfaction questionnaire one year after surgery. 92% of the patients were satisfied with sur-

gery, 100% believed they made the right decision when undergoing surgery, 91.5% perceived that the information they received before surgery prepared them adequately, 100% would do their procedure again, 100% would recommend it to other patients, the surgery met the expectations of 85.5%, specific details on Table 2.

Table 1. Comparative results of MDS-UPDRS clinimetrics scales part I, II, III, IV, Total, NMSS by domain total and PDQ-8.

	Baseline visit	Subsequent visit	p
MDS-UDPRS I	11.60 ± 1.17	9.59 ± 1.05	0.972
MDS-UDPRS II	12.98 ± 1.5	11.61 ± 1.58	0.356
MDS-UDPRS III	24.66 ± 2.7	24.47 ± 2.29	0.486
MDS-UDPRS IV	2.68 ± 0.63	4.83 ± 0.8	0.239
MDS-UDPRS Total	40.74 ± 3.95	46.74 ± 3.95	0.089
NMSS Cardiovascular	2.0 ± 0.56	1.74 ± 0.52	0.665
NMSS Sleep/fatigue	8.55 ± 1.58	7.86 ± 1.35	0.712
NMSS Humor/cognition	11.57 ± 2.45	7.96 ± 2.23	0.235
NMSS Hallucinations	1.19 ± 0.45	1.51 ± 0.86	0.742
NMSS Attention	3.81 ± 0.97	3.45 ± 0.91	0.752
NMSS Gastrointestinal	4.34 ± 0.99	6.68 ± 1.45	0.04*
NMSS Urinary	11.23 ± 3.29	7.91 ± 1.4	0.291
NMSS sexual function	2.19 ± 0.79	3.11 ± 0.97	0.4
NMSS miscellaneous	7.96 ± 1.34	8.36 ± 1.4	0.769
NMSS Total	54.85 ± 8.3	50.74 ± 7.33	0.6
PDQ-8	8.09 ± 0.97	9.45 ± 1.02	0.205

MDS-UPDRS = Movement Disorder Society-Unified Parkinson's Disease Rating Scale, NMSS = NON-MOTOR SYMPTOMS SCALE, PDQ-8 = PARKINSON'S DISEASE QUESTIONNAIRE-8.

Table 2. Semi-structured post-surgical satisfaction questionnaire.

Questions	n = 20 (range)
1. How satisfied are you with the overall result of the surgery?	92% (100 - 70)
2. Do you think you made the right decision about surgery?	Yes 100%
3. To what extent do you think the information you received prior to surgery prepared you?	91.5%
4. Would you do it again?	Yes 100%
5. Would you recommend it to other patients?	Yes 100%
6. Overall, to what extent has your surgery met your expectations?	85.5% (100 - 0)
7. Anything particularly good about the surgery you had?	Everything 30%
8. Anything particularly bad about the surgery you had?	No Comments 70%

4. Discussion

The high level of satisfaction presented by this population of PD patients on DBS therapy is concordant with previous descriptions in which quality of life, expectations, and patient satisfaction were evaluated. We did not find a progression of non-motor symptoms by NMSS scale between baseline and subsequent postoperative visits despite the meantime after surgery (mean 3.18 years), time with the disease (mean 13.42 years), and disease progression, concordant with the results obtained by other studies [13] [18].

Concerning the quality of life by the PDQ8 scale, we found no significant difference between the baseline and the subsequent postoperative visit, showing no worsening in the quality of life of the patients who underwent DBS.

Assessments of the MDS UPDRS scale and its different domains (part I, II, III, and IV) during the ON period showed a discrete improvement in postoperative scores, but these were not statistically significant. Despite a non-significant improvement in the motor scores, these were not high (>30 points) or disabling scores, which tells us about the clinical stability associated with DBS. We observed progression regarding baseline in postoperative part IV, which may be associated with disease progression and higher motor complications related to the chronic use of levodopa.

Treatment satisfaction is a multidimensional concept broadly related to the outcome or the process. Satisfaction with results after DBS surgery has been assessed by interviews and questionnaires [19] [20]. One study showed that up to 25% of patients perceive a negative effect one year after surgery. Preoperative apathy and axial symptoms predicted dissatisfaction with DBS in the STN [20].

Also, patients with perceived disapproved outcomes had unrealistic preoperative expectations, no improvement in quality of life, and significantly higher preoperative and postoperative apathy and depression scores [19]. Another study showed that six-month satisfaction correlated with meeting expectations [18].

Patients reported high satisfaction levels, even with discouraging results on clinimetric scales. Medications and their side effects, surgery complications, and follow-up adjustments are related to patient satisfaction.

A risk of selection bias may present when none of the patients in this cohort had significant complications related to the surgical procedure, compared to patients who experience adverse events and may report lower satisfaction and disparity between actual and expected outcomes [18]. Besides, patients may not fully report complications to healthcare personnel. Another limitation is that the satisfaction assessment questionnaire is not a validated tool. Despite these limitations, the role of satisfaction level after DBS has received little attention, and we believe that these results remark on the importance of assessing expectations of DBS for Parkinson's disease that deserves further study.

5. Conclusion

Our study showed that PD patients were satisfied with DBS. Even when the

quality of life and the motor and non-motor experiences of daily life did not improve significantly showed clinical stability and less disease progression, consistent with the existing evidence on the effectiveness of DBS in advanced stages of the disease. Patients' expectations change over time. Therefore, their evaluations before and after surgery are essential for PD patient satisfaction.

Conflicts of Interest

The authors declare no conflicts of interest regarding the publication of this paper.

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