



## Short communication

## Patients' reluctance to undergo deep brain stimulation for Parkinson's disease



Mi-Ryoung Kim <sup>a,1</sup>, Ji Young Yun <sup>b,1</sup>, Beomseok Jeon <sup>c,\*</sup>, Yong Hoon Lim <sup>a</sup>,  
Kyung Ran Kim <sup>a</sup>, Hui-Jun Yang <sup>d</sup>, Sun Ha Paek <sup>a,\*\*</sup>

<sup>a</sup> Department of Neurosurgery, Movement Disorder Center and Neuroscience Research Institute, Seoul National University Hospital, Seoul, Republic of Korea

<sup>b</sup> Department of Neurology, Ewha Womans University Mokdong Hospital and Ewha Womans University School of Medicine, Seoul, Republic of Korea

<sup>c</sup> Department of Neurology, Movement Disorder Center and Neuroscience Research Institute, Seoul National University Hospital, Seoul, Republic of Korea

<sup>d</sup> Department of Neurology, Ulsan University Hospital, University of Ulsan College of Medicine, Ulsan, Republic of Korea

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## ABSTRACT

**Background:** Many patients with advanced Parkinson's disease (PD) are reluctant to undergo the subthalamic nucleus deep brain stimulation (STN-DBS) when surgery is warranted. Reasons for this reluctance have not been examined. We undertook to establish the rate and causes of this reluctance for STN-DBS in patients with advanced PD.

**Methods:** A reluctant group was defined as patients who were hesitant to undergo DBS. Clinical information included age, onset age, disease duration, the Unified Parkinson Disease Rating Scale, Hoehn and Yahr stage and levodopa equivalent dose when they were evaluated with a view to consider surgery.

**Results:** We enrolled 186 patients who underwent STN-DBS. 84 patients (45%) belonged to the reluctant group. Between the reluctant and the non-reluctant, there were no differences in preoperative characteristics. Main reasons for hesitation were fear of complications (74%) and economic burden (50%). The main reasons that they finally underwent the DBS were confidence in the doctor's decision (80%) and encouragement from their family (36%).

**Conclusions:** Building trust between patients and physicians is an important factor in guiding patients to undergo this treatment. To reduce the reluctance to undergo DBS at the appropriate time, we need to find effective ways of reducing their psychological and economic burden.

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## 1. Introduction

Subthalamic nucleus deep brain stimulation (STN-DBS) is a well-recognized treatment for reducing disabling motor fluctuations or dyskinesia in advanced Parkinson's disease (PD) [1–4].

In PD, STN-DBS is indicated in patients with intolerable motor fluctuations, dyskinesia, drug adverse events, or tremor [5]. Nonetheless, when clinicians recommend DBS, many patients and caregivers are reluctant for the patient to undergo STN-DBS. The unwillingness to undergo STN-DBS and subsequent delay in surgery prolong patients' distress resulting from disabling motor

fluctuations or dyskinesia.

The gender, education level, employment and position in society are known to be contributing factors when making the decision to undergo DBS [6]. However, no studies have examined the reasons why patients who are good candidates for STN-DBS are reluctant to proceed. In this study, the rate and causes of reluctance to undergo STN-DBS were examined in patients with advanced PD.

## 2. Methods

All pre-surgical evaluations were carried out by neurologists under a prospective protocol approved in 2005 [7]. Pre-operative evaluations included: Unified Parkinson Disease Rating Scale (UPDRS), Hoehn and Yahr staging (HY), levodopa equivalent daily dose (LEDD), dopamine agonist levodopa equivalent daily dose (DA-LEDD), off-duration, dyskinesia-duration, dyskinesia-severity, Mini Mental State Exam (MMSE) and Beck depression inventory (BDI). Patients' employment status and primary referral source

\* Corresponding author. Department of Neurology, Seoul National University Hospital, 28 Yongon-dong, Chongno-gu, Seoul, 110-744, Republic of Korea.

\*\* Corresponding author. Department of Neurosurgery, Seoul National University Hospital, 28 Yongon-dong, Chongno-gu, Seoul, 110-744, Republic of Korea.

E-mail addresses: [brain@snu.ac.kr](mailto:brain@snu.ac.kr) (B. Jeon), [paeksh@snu.ac.kr](mailto:paeksh@snu.ac.kr) (S.H. Paek).

<sup>1</sup> MRK and JYY contributed equally.

were recorded. A recommendation for surgery was made based on the evaluation results.

Patients' preoperative expectations were assessed with a questionnaire: "What is your expectation of STN-DBS?" Possible answers were "shorter off-duration", "more tolerable off-symptoms", "less intolerable dyskinesia", "dose reduction of antiparkinsonian medication", "improvement of activities in daily life."

The group reluctant to undergo STN-DBS was defined as patients who replied that they were reluctant to undergo surgery. The other group included patients who replied that they were not reluctant to undergo the surgery (non-reluctant group). A retrospective survey was conducted using closed-ended questions with written questionnaires and telephone interviews, for which the patients answered questions about the following: their reluctance to undergo surgery, three important reasons for delaying the surgery, and three important reasons for undergoing the surgery. For the reasons for delaying the surgery and for the three biggest reasons for undergoing the surgery, multiple answers were allowed. In addition, in the reluctant group, the reasons why they changed their mind to undergo STN-DBS were also surveyed.

The Institutional Review Board (IRB) of Seoul National University Hospital (SNUH) approved this study. Requirement for informed consent was waived for this retrospective analysis of clinical data. The IRB also waived the need for consent. All statistical analyses were performed with SPSS 21.0 (SPSS Inc., Chicago, IL, USA). Comparisons between the reluctant and non-reluctant group were analyzed with independent t-test. Chi-square test was used to evaluate the differences in gender between the two groups.

### 3. Results

This study included advanced PD patients, who underwent STN-DBS between March 2005 and June 2014 at the Movement Disorder Center, SNUH. During the study period, a pre-surgical evaluation was performed in 362 patients. After the pre-surgical evaluation, we recommended STN-DBS to 201 patients. Three patients refused STN-DBS fearing adverse events. A total of 198 patients underwent STN-DBS. Three patients were lost to follow up and the 9 patients who died were excluded from the survey.

A total of 186 PD patients, who underwent STN-DBS were included in the analysis. When multiple surgeries were performed, the survey was administered before the first surgery. Eighty-four (45%) out of 186 patients were initially reluctant to undergo surgery. The period between the pre-surgical evaluation and STN-DBS surgery was  $9.79 \pm 10.99$  months (range = 1–48 months) in the reluctant group and  $1.67 \pm 1.34$  months (0–5 months) in the non-reluctant group, and was significantly different ( $p = 0.001$ ).

There was no significant difference between the age at the time of the recommendation for DBS and surgery, disease duration, LEDD, DA-LEDD, dyskinesia-duration, dyskinesia-disability, off-duration, HY stage, and the mean UPDRS motor scale and total score. In addition, their expectation regarding STN-DBS were not significantly different (Table 1).

The main reasons for the reluctance to undergo DBS were fear of adverse events ( $N = 62$ , 74%), financial burden (42, 50%) and, hope for new-non surgical treatments (29, 35%, Fig. 1). Interruption in social routines including jobs around the surgery (14, 17%) probably is a convenient excuse for reluctance. Ten patients (12%) wanted to delay the operation because of comorbidities including back pain ( $N = 5$ ), cardiac disease (2), osteoarthritis (1), diabetes (1) and trauma (1). Five patients were reluctant to undergo STN-DBS because of cosmetic problems following surgery (6%).

In regards to the economic burden associated with STN-DBS, 22 patients asked for financial from their family members including their children ( $N = 15$ ), spouses (5), and siblings (2). Fourteen

patients received financial support through the social services of the Hospital including the social welfare fund ( $N = 14$ ). In addition, 3 patients borrowed money from private loans ( $N = 2$ ) or a bank (1). One patient delayed the STN-DBS surgery until he had saved enough.

For the 42 patients who were financially burdened because of surgery, they also had economic difficulties in the post-operatively ( $N = 28$ ), due to the replacement cost of impulse generators (26) and travel costs (11).

The main reasons for subsequently agreeing to undergo DBS were increased confidence in the clinician's decision ( $N = 67$ , 80%), encouragement from family members (30, 36%), financial assistance for the cost of surgery (15, 18%), learning more about DBS (12, 14%), worsening symptoms (6, 7%) and recovery from their comorbid medical problems (5, 6%).

### 4. Discussion

This survey shows that many patients found to be good candidates to DBS were reluctant to undergo DBS. The key reasons for the hesitation were fear of side effects and financial burden.

Although the National Health Insurance Service (NHIS) reimburses the cost of STN-DBS, the financial burden was the second most common cause for hesitation. The coverage provided by the Korean NHIS is relatively comprehensive and typical patient co-payment costs are 20% in the case of inpatient hospital care. PD is registered as a "rare and incurable" disease in Korea, and the co-payment is further reduced to only 10% [8]. As some services are not covered by NHIS, mean expenses paid by the patients for DBS including preoperative work-up is around USD 9300 at our center. Given that the Korean average household net-income is USD 19,510 a year [9], the financial burden can be a significant reason for not undergoing surgery.

Pre- and post-operative factors have to be included when taking economic considerations into account for STN-DBS [10]. In our study, in addition to the cost of the operation, the reluctant group was unwilling to undergo STN-DBS because of replacement cost of an impulse generator, and travel costs. Therefore, in order to make surgery less expensive and thus allow patients to proceed to surgery in timely manner, a more effective and comprehensive financial support package is needed.

Dopamine agonists (DA) can make patients more impulsive when making decisions and increase risk taking behaviors [11,12]. DA-LEDD tended to be higher in the non-reluctant group in our study, however, there was no statistical significance. The gender, education level, employment, position in society and referral centers are known as contributing factors in the decision-making process to undergo DBS [6]. However, they were not significantly different between the two groups.

The major reason for patients eventually deciding to undergo surgery was the increased trust they had in their doctors following counseling (66, 79%). This shows that the trust between patients and clinicians is important.

Encouragement from family members was the second most common cause for changing their decision to undergo STN-DBS (30, 36%). It is possible that the family members might have their own reasons for the patient deciding whether to undergo STN-DBS. However, we did not study these reasons in this study. In particular, we did not investigate the carer costs or time spent caring for a PD patient.

A few of the patients (12, 14%) needed repeated counselling before (12, 14%) changing their decision. During these sessions, the surgical risks and benefits were thoroughly discussed to reduce in order to reduce the patient's anxiety. The encouragement from family members played an important role in changing the patient's decision. Therefore education should be offered not only to patients

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