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Assessing Quality of Life for Individuals with Parkinson's Disease with and without Deep Brain Stimulation: The Development and Initial Results of The Parkinson Alliance Quality of Life Scale (PAQLS)

INTRODUCTION

Deep Brain Stimulation (DBS) has emerged as an effective treatment for many of the motor symptoms of PD and typically results in an improvement in health related quality of life (QoL) (Benabid, Chabardes, & Seigneuret, 2005). There is a strong interest in understanding how individuals perceive and understand DBS as well as the effect of DBS on symptom severity and quality of life. Prompted by our previous research (Tuchman et al., 2004; Wertheimer et al., 2004) and limitations of existing PD-specific QoL measures, The Parkinson Alliance designed a QoL survey with the intention of creating a unique and comprehensive self-report measure of QoL in PD patients. **The goal of our research was to gain insight into the QoL of individuals with Parkinson's disease who have and have not undergone DBS.**

OBJECTIVES

- To create a new self-report survey designed to assess QoL in patients with PD who have and have not undergone DBS of the subthalamic nucleus (DBS-STN).
- To examine how certain patient variables relate to QoL domains.
- To assess symptom and QoL differences in individuals with PD with and without DBS-STN.
- To develop a survey specific to assessing the impact that DBS has on QoL and understanding patient satisfaction with 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, 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), or our affiliate website devoted to DBS (www.dbs-stn.org). Although 45 percent of the respondents were from the states of New Jersey, New York, or California, the other respondents represent a broad geographical range, with a total of 30 additional states represented. Each participant was mailed and returned an informed consent form, the Parkinson Alliance Quality of Life Scale (PAQLS) and a supplemental questionnaire assessing demographics and other clinical characteristics of the sample. The participants in this report included 94 individuals with PD who underwent DBS (of whom 90 had bilateral DBS-STN and 4 of

whom had DBS to the Globus Pallidus [GPi]) and a comparison group of 86 individuals with PD without DBS.

As mentioned above, although we have used other measures of quality of life in our previous research, we felt that after a thorough review of all available instruments in the scientific literature, there was room for improvement in the questionnaires assessing QoL. Specifically, our previous research results have supported the view that both motor and non-motor symptoms are important to assess in PD. Additionally, we have found that speech problems are a common complaint among individuals with DBS-STN and few questionnaires available adequately assess this potential complication of DBS surgery. We also learned that additional non-motor symptoms, including sleep, anxiety, depression, and cognitive symptoms are important to assess, yet, they are not very well covered in other questionnaires. Finally, we have found only one questionnaire that specifically addresses DBS specific issues (Kuehler et al., 2003), such as satisfaction with DBS and other relevant variables related to DBS (e.g., programming, adjustments, etc). For these reasons, The Parkinson Alliance Research Team developed the PAQLS to help provide a thorough and comprehensive measure of QoL in PD and DBS. This summary is our first report of our work using this scale and the initial results follow.

RESULTS

Table 1 shown below summarizes the demographic and clinical information about the sample. We collected data from a large, representative group of PD patients spanning a broad range of age and clinical symptoms. The average age of PD onset was 45.6 for the DBS group and 54.8 for the non-DBS group. Both genders are equally represented for each group (Male: DBS=57%; non-DBS=53%; Female: DBS=43%; non-DBS=47%). Most of the patients were married (DBS=76%; non-DBS=77%) and not working (DBS=81%; non-DBS=71%).

Table 1. Demographics and clinical features of the sample.

Variable	DBS	Non-DBS
Mean Age in years	62	62.6
Duration of PD in years *	15.6	8.2
Percent Male	57%	53%
Percent Female	43%	47%
Percent Married	76%	77%
Mean Age of PD onset (in years)*	45.6	54.8
Average Time since DBS-STN (in years)	3.5	n/a
Percent Not Working*	81%	71%
Percent In Need of a Carer*	48%	36%
Percent Driving*	56%	71%
Percent Currently in a PD Support Group	54%	64%

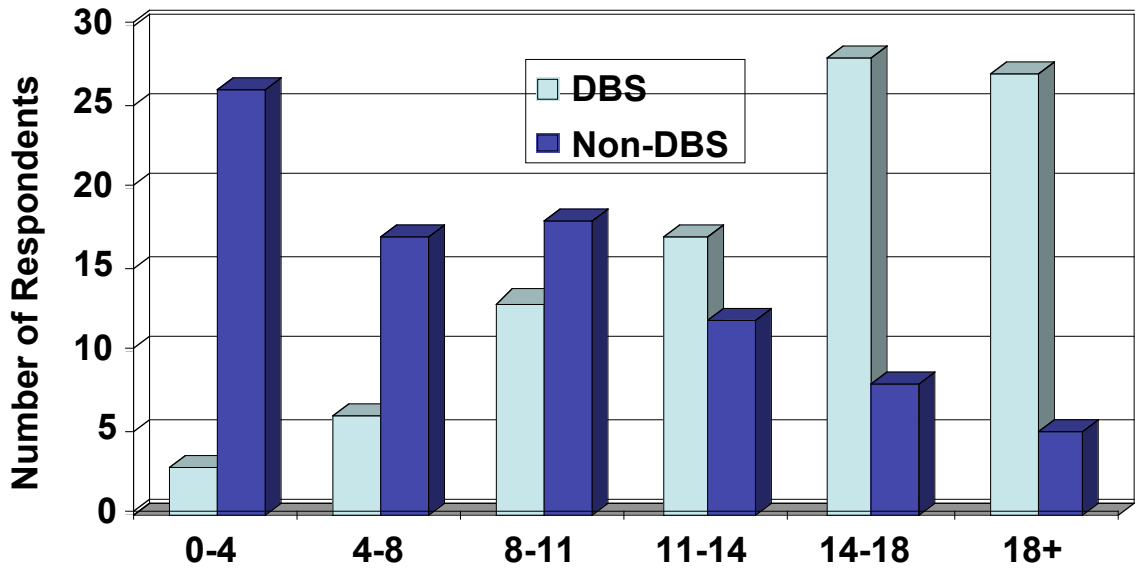
* denotes significant differences between the groups

Although the respondents from both groups were closely matched in terms of age, gender, and marital status, there are other important and statistically significant differences between the two groups on several demographic and clinical variables. Although the majority of respondents in both groups are not working, fewer DBS participants are working compared to the non-DBS group. Also, a greater number of non-DBS participants reported driving an automobile compared to the DBS group. The age of PD onset was earlier in the DBS group than the non-DBS group and the DBS group reported needing a carer more frequently than did the non-DBS group. A majority of respondents in both groups reported current engagement in a PD support group.

Duration of PD within the two groups:

One of the most important components of this research project was interpreting the data with the consideration for the differences of disease duration between the two groups. Although a large number of individuals participated in this research project, it was difficult to match for disease duration at specific points wherein the duration was comparable. As you will see, the groups were almost mirror images of each other; the graphs below illustrate the differences in disease duration between the two groups. The individuals were categorized into the following increments: 0-4 years, 4-8 years, 8-11 years, 11-14 years, 14-18 years, and 18+ years. *Because disease duration likely explains some of the differences between the two groups, all analyses reported below statistically controlled for disease duration.*

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

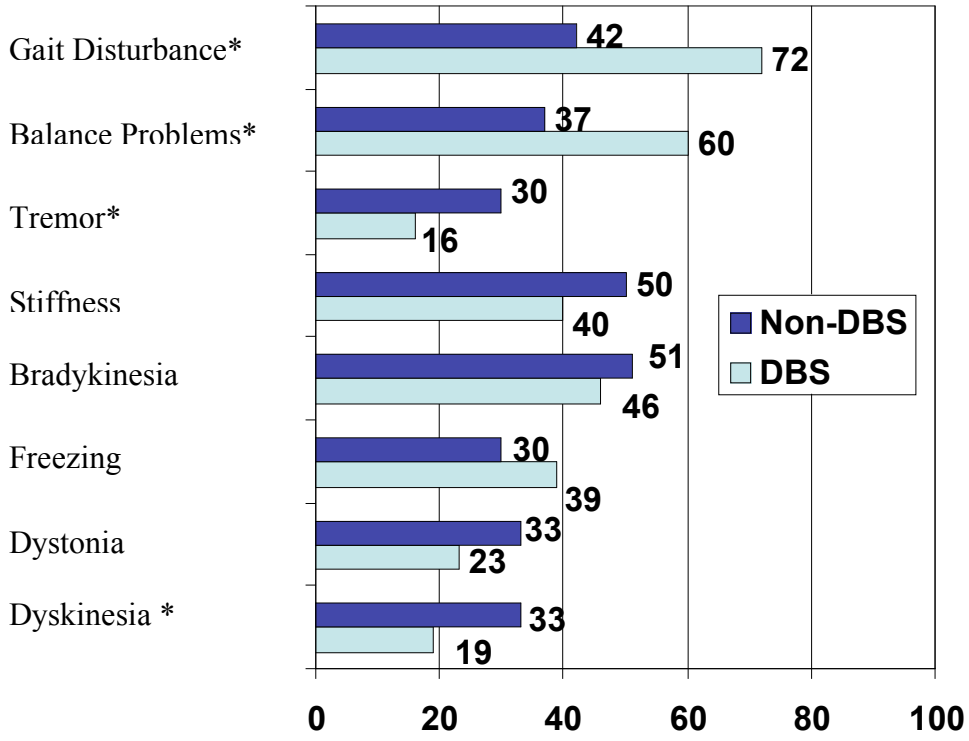


Motor Symptoms:

Motor symptoms are the cardinal symptoms of Parkinson's disease. In this research project, the following figure will illustrate the percentage of respondents who reported experiences of common motor symptoms of PD. With regard to the group differences in motor symptoms, there were no significant differences between the DBS and non-DBS groups on the following symptoms: bradykinesia, stiffness, freezing, or dystonia, and number of falls. In contrast, there were significant

differences between the following symptoms: poor balance, gait disturbance, dyskinesia, and tremor. Specifically, individuals with DBS reported less symptoms of tremor and dyskinesia, but they reported more symptoms of gait disturbance and poor balance (see Figure 2).

Figure 2. Percent reporting the experience of motor symptoms



* Denotes significant differences between the two groups

Motor Symptoms and Quality of Life:

With regard to the relationship between motor symptoms and quality of life, as expected, motor symptoms (gait disturbance, poor balance, tremor, stiffness, bradykinesia, freezing, and dystonia) are significantly correlated to overall negative quality of life for both groups. Overall, in this sample, worse motor symptoms was associated with poorer self-reported quality of life regardless of whether the person has had DBS or not.

Summary of Non-Motor Symptoms:

Non-motor symptoms and QoL

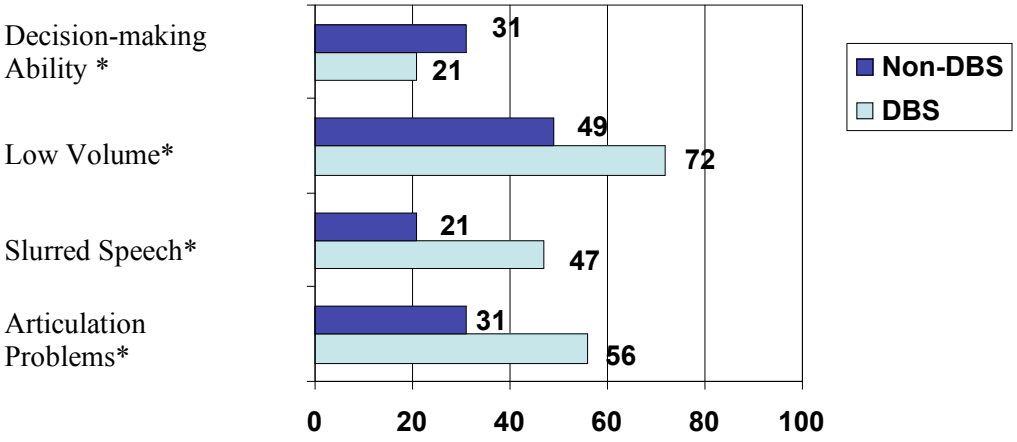
For the sake of simplicity, only a few of the non-motor symptoms investigated in this research project are addressed in this report. The selected non-motor symptoms were categorized into

four areas, psychological distress, speech, cognition, and sleep. As expected and consistent with other research, the variables of psychological distress, speech related problems, cognitive and sleep symptoms were all significantly negatively associated with overall Quality of Life. Interestingly, for the non-DBS group, cognitive-related problems were found to have a higher correlation with quality of life than for the DBS group. Also, the DBS group reported a stronger relationship between sleep quality and overall quality of life. Overall, a significant percentage of both groups were experiencing problems with non-motor symptoms, which highlights the importance of non-motor symptoms in PD.

Non-motor symptoms, differences between groups:

There were no significant differences between emotional/distress variables and sleep-related variables between groups. However, with regard to speech, there were significant differences between the DBS and Non-DBS group, with the DBS group reporting more problems in the areas of low volume, slurred speech, and speech articulation (See Figure 3). An intriguing finding was related to the difference in how the groups perceive their cognition. Specifically, when inquiring about perceived cognitive ability, the DBS group reported fewer problems than the non-DBS group with regard to decision-making ability and there was a trend toward better self-report memory functioning in the DBS group. There was an absence of differences with regard to perceived problems with concentration, word-finding problems, trouble thinking clearly, difficulty planning/organizing, slowed thinking, and impulsivity.

Figure 3 - Differences between Non-motor Symptoms: Percent reporting Moderate to Severe Symptoms



* Denotes significant differences between the two groups

DBS Specific Questionnaire:

For this preliminary report, we summarized several findings from the DBS-specific portion of the PAQLS. First, we summarize descriptive data for respondents' level of satisfaction with

several important aspects of DBS (See Table 4 below). Then, we give a qualitative summary of symptoms most relieved by DBS.

Table 4. Percentage of DBS Group Reporting Satisfaction and Dissatisfaction with Various Features of DBS and DBS-Related Treatment Variables

Variable	Satisfied	Dissatisfied
Overall Effect of DBS	94 %	6 %
Post-Surgical Follow-Up	83 %	17 %
Satisfied with Programmer	91 %	9 %
Distance to Travel to Programmer	57 %	43 %
Satisfaction with Speech	42 %	58 %
How the Neurostimlator Operates	93 %	7 %
Medication Reduction Expectations	73 %	27 %
On/Off Reduction Following DBS	80 %	20 %
Weight Following DBS	55 %	45 %
Stability of Improvement	82 %	18 %
Satisfied with DBS Over Time	81 %	19 %

Most participants reported relatively high levels of satisfaction with the process and outcome of the DBS therapy. Inspection of the individual items revealed that the majority of the participants were satisfied with the overall effect of DBS, post-surgical follow-up, the programmer, how the neurostimlator operates, expectations of medication reduction, On/Off reduction following DBS, stability of improvement, and satisfaction with DBS over time. It is worth noting that the data reflects that there are a large number of participants who were dissatisfied with the distance they have to travel to meet with a programmer, speech problems, and weight following surgery (most often weight gain).

There were many DBS variables that were related to quality of life for the participants with DBS. Factors that were related to quality of life included satisfaction with DBS over time, stability of improvement, the reduction of On/Off episodes, reduction of medications, the

programmer, speech, post-surgical follow-up, and one's weight. There were a couple of variables that did not appear to significantly relate to quality of life, such as the distance one has to travel to get to the programmer and how the neurostimulator operates.

DBS was reported to impact many symptoms related to Parkinson's disease, and the table below illustrates the percentage of individuals with DBS who endorsed some symptom relief as a result of DBS therapy (See Table 5).

Table 5. Percentage of DBS patients who endorsed some improvement:

Symptom	Percentage %
Tremor	60
Dyskinesias	54
Rigidity	50
Freezing	49
Gait Difficulties	48
Loss of balance	46
Handwriting	45
Bradykinesia	34
Fatigue	18
Social Isolation	12
Insomnia	9
Speech Problems	8
Depression	7
Swallowing Problems	6
Memory Problems	6
Cognitive problems	5

DISCUSSION

- Understanding quality of life and symptoms for patients with PD, from the perspective of the patient, is of great importance. This study sought to examine symptoms common to PD and how they relate to quality of life for both patients with and without DBS and to examine differences between these two groups.

- With consideration for the difference in disease duration between groups, one can speculate from the results of this research project that the DBS group is, overall, functioning at levels comparable to those who have had PD for nearly half as long. Moreover, the DBS group's responses were not statistically different from the non-DBS group on many factors, which may imply that DBS is assisting the PD patient in reducing the symptoms that would otherwise be worse.

- The DBS group reported fewer problems with tremor and dyskinesias and this finding is consistent with the literature (Benabid, Chabardes, & Seigneuret, 2005; Lyons & Pahwa, 2005). In this study, there were significantly more reports of balance problems for the DBS group than the non-DBS group. Interestingly, in contradiction with some research, the DBS group reported more problems with gait than the non-DBS group.

- PD patients with and without DBS report similar experiences with non-motor symptoms.
    - Emotional/psychiatric symptoms are both very prevalent (e.g., depression and anxiety), and they are highly related to quality of life, as expected. Due to the prevalence of emotional factors and significant relationship to QoL, appropriate monitoring and management thereof is warranted.
    - Although sleep disturbances were prevalent within each group (e.g., excessive daytime sleepiness), there was not a significant difference between the two groups.
    - Speech problems continue to be one of the most frequently reported troubling symptoms among the DBS sample, and although the non-DBS group reported problems in this area as well, there was a significant difference between the two groups, with the DBS group reporting more problems with low volume, speech articulation, and slurred speech.
    - Some participants in both groups reported perceived problems with cognition (e.g., attention, memory, thinking clearly, decision-making capability). Interestingly, there was a statistically significant difference between perceived problems and decision-making ability, with the DBS group reporting fewer complaints in this area.

- Most participants who have undergone DBS reported satisfaction with the treatment and outcome related to DBS therapy. There were only a few treatment- or outcome-related variables that revealed dissatisfaction with the procedure and they included distance to travel to meet with a programmer, speech problems, and weight gain.

- In spite of the limitations of a questionnaire survey, it has proved to be useful in gaining a better understanding of the experience of individuals with Parkinson's disease with and without DBS.

FUTURE DIRECTIONS

1. The Parkinson Alliance emphasizes the importance of investigating the participants' experience with DBS-STN across time, and we are currently examining quality of life factors for individuals with DBS with a duration-matched comparison group using The Parkinson Alliance Quality of Life Survey (PAQLS).

2. The PAQLS has demonstrated some interesting results and adds to the understanding about patients' perspectives regarding DBS therapy and its benefit; follow-up research

projects will further elucidate this instrument's utility and efficacy for patients with Parkinson's disease.

3. Future research is called for to investigate in greater degree the impact of and relationship between sleep and anxiety for patients with PD with and without DBS.

ACKNOWLEDGEMENTS

As we complete our fourth DBS-STN patient survey, 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 three neuropsychologists who analyze the data and add their professional skills to our work, including Dr. Jeffrey C. Wertheimer, staff neuropsychologist for Brooks Rehabilitation Hospital, Dr. Julie Smith, staff neuropsychologist for Henry Ford Hospital, and Dr. Lisle Kingery. 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

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