Quality of Life and Attitude in Individuals with Parkinson’s Disease with and without Deep Brain Stimulation

Introduction

Individuals with Parkinson’s disease (PD) are confronted with physical, psychological, and psychosocial issues that impact quality of life (QoL). The medical community is increasingly recognizing health-related quality of life as a major criterion in evaluation of health interventions, particularly, as it relates to PD, in the context of both motor and non-motor symptoms.

There are many coping techniques that can be helpful in adapting to PD. Research has pointed out that maintaining a positive attitude, optimism, and happiness can lead to longer lives, less disability, and increased QoL. Frazier and Marsh encourage individuals to regard PD obstacles as challenges to be overcome, rather than hopeless barriers. They indicated that a positive approach to coping with PD allows for a sense of pride, control, and hopefulness that can lead to more effective coping and quality of life. In a previous study conducted by The Parkinson Alliance, having a positive attitude and using proactive coping techniques were found to have the greatest impact on quality of life when compared to other coping mechanisms.

Objectives

1. To examine the characteristics of QOL in People with Parkinson’s (PWP) using the Parkinson’s Disease Questionnaire – 39, particularly as it relates to those who have undergone DBS (DBS group) and those who have not had DBS (Non-DBS group).

2. To investigate attitude in PWP.

3. To look at QOL and attitude over time in individuals with PD who have and have not undergone DBS therapy.

Methods

The participants in this report included 587 individuals with PD, 229 participants in the DBS group and 358 individuals in the Non-DBS group. Please see Table 1 for the demographic information. The participants were recruited from a variety of sources. The data collected in this study represents individuals who were invited to participate in the current survey due to previous survey participation; responded to study announcements in medical clinics around the country; found out about the study through their participation in local PD support groups; or responded to survey announcements located on The Parkinson Alliance website (www.parkinsonalliance.org) or our affiliate website devoted to DBS (www.dbs-stn.org). The participants either completed a paper-and-pencil survey or an on-line survey, depending on their preference.
Assessment Questionnaires: The participants in this study completed a Demographics questionnaire, questions related to positive and negative attitudes, and The Parkinson's Disease Questionnaire-39.

The Demographic Questionnaire and questions related to attitude: The demographic questionnaire included questions related to background information of the participants as well as questions related to having a positive or negative attitude in the context of their PD symptoms. With regard to positive and negative attitude, participants were given statements to which they responded “never,” “sometimes,” “often,” and “always” (with corresponding numerical values of zero to three, respectively). An average score on a range of 0 to 3 was created for both the positive attitude and negative attitude variables (higher scores reflect highly positive or negative attitudes).

Examples of statements reflecting positive attitude:

- When faced with a physical or mental challenge due to my PD, I am most likely to face the challenge head-on and do what it takes to overcome it.
- I treat the symptoms of PD as a challenge that I will readily overcome.
- When I go to my medical appointments, I go in with positive expectations about what the doctor will say.
- I believe that if I maintain a positive attitude that I will have less stress and a better chance of dealing with PD.
- When I am having a bad week due to PD, I do all that I can to remain upbeat.
- Even when I have worsening of my PD symptoms, I can create positive change within my life.

Examples of statements reflecting negative attitude:

- When I am faced with difficulties, I often have negative thoughts (e.g. I can't do it, I'll never get this done) regarding my ability to overcome challenging situations.
- I tend to dwell on all of the failures of all the treatment they have tried for my PD.
- If I receive bad news from my physician I am likely to say, “That’s it, there is no need for me to try anymore.”
- I tend to dwell on all of the failures of all the treatments that have been tried for my PD.
- I feel as though PD is winning and I am losing.
- It is difficult for me to have a positive attitude.

The Parkinson's Disease Questionnaire - 39 (PDQ-39):

The PDQ-39 has 39 items and measures health-related problems or difficulties that are commonly experienced by individuals with PD. This instrument is a measure assessing health-related quality of life, which simply illustrates the level of difficulty one is experiencing in a specific functional domain.

The PDQ-39 has eight domains and one single index, an aggregate score for the domains. The eight domains include: Mobility, Activities of Daily Living, Emotional Wellbeing, Stigma, Social Support, Cognitions, Communication, and Bodily Discomfort. The responses in each domain are calculated and transformed to have a range from 0 (best, i.e., no problem at all) through 100 (worst, i.e., maximum level of problem). Higher scores reflect greater difficulties/problems. The findings illustrate the level of difficulty individuals with PD are experiencing in specific functional domains.
Results

Table 1. Demographics and Clinical Features of the Sample

<table>
<thead>
<tr>
<th>Variable</th>
<th>DBS (N=229)</th>
<th>Non-DBS (N=358)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Average Age in Years*</td>
<td>64</td>
<td>70</td>
</tr>
<tr>
<td>Duration of PD in Years</td>
<td>16.0</td>
<td>8.5</td>
</tr>
<tr>
<td>Average Age of PD Onset *</td>
<td>48</td>
<td>61</td>
</tr>
<tr>
<td>Male</td>
<td>64%</td>
<td>60%</td>
</tr>
<tr>
<td>Female</td>
<td>36%</td>
<td>40%</td>
</tr>
<tr>
<td>Married</td>
<td>71%</td>
<td>74%</td>
</tr>
<tr>
<td>Living with Someone</td>
<td>87%</td>
<td>89%</td>
</tr>
<tr>
<td>Age at Time of DBS in Years (Range)</td>
<td>59 (31-80)</td>
<td>n/a</td>
</tr>
<tr>
<td>Duration since DBS in Years (Range)</td>
<td>5.5 (0-14)</td>
<td>n/a</td>
</tr>
<tr>
<td>DBS Target</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Subthalamic Nucleus (STN)</td>
<td>88%</td>
<td>n/a</td>
</tr>
<tr>
<td>Globus Pallidus interna (GPi)</td>
<td>7%</td>
<td>n/a</td>
</tr>
<tr>
<td>Thalamus</td>
<td>5%</td>
<td>n/a</td>
</tr>
<tr>
<td>Bilateral Stimulation</td>
<td>81%</td>
<td>n/a</td>
</tr>
<tr>
<td>Unilateral Stimulation</td>
<td>19%</td>
<td>n/a</td>
</tr>
</tbody>
</table>

* Denotes significant differences between the groups

Age and Duration of PD for the DSB and Non-DBS groups:

There was a significant difference for duration of PD between the two groups (see Table 1 and Figure 2). The DBS group had PD for a longer duration than the Non-DBS group. For research purposes, the duration of PD was taken into consideration for all of the results reported below.
Positive Versus Negative Attitude (Comparing DBS and Non-DBS groups):

- In the context of having PD symptoms, the majority of both the DBS and Non-DBS groups had a positive attitude.
- The average rating of positive attitude fell between “Often” and “Always” having a positive attitude as it relates to their ability to face the challenges related to PD.
- The converse was true for negative attitude, where the majority of participants indicated that they “never” or only “sometimes” engage in negative thinking about their ability to face challenges related to the symptoms of PD.
- There was not a clinically significant difference of positive or negative attitudes between the DBS and Non-DBS groups.

Health-Related Quality of Life – Parkinson’s Disease Questionnaire-39 (PDQ-39):

- The summary of the PDQ-39 information for this study can be found in Figure 3. Note that lower scores reflect a better rating of health-related quality of life (0=best rating/no difficulties with symptoms assessed; 100=worst rating/always having difficulties with symptoms assessed).
- The DBS group had a modestly worse rating of health-related quality of life than the Non-DBS group.
- The difference in health-related quality of life for these two groups was influenced by 3 of the 8 domains, including mobility, social support, and communication. When compared to the Non-DBS group, the DBS group endorsed greater difficulties with getting around in general (Mobility) and with communicating with others, and the DBS group reported having less support from social relationships.
- In contrast, the DBS group and Non-DBS group had similar ratings of health-related quality of life/difficulties on the following domains: Activities of Daily Living (such as completing basic tasks such as washing and dressing oneself), Emotional Well-being, Stigma (such as feeling the need to hide PD from others, feeling embarrassed about having PD), Cognitions (such as problems with concentration and memory), and Bodily Discomfort (such as painful muscle cramps and aches and pains in joints).

Figure 3. The Parkinson’s Disease Questionnaire (PDQ-39) for DBS and Non-DBS groups:
Gender Differences in Health-Related Quality of Life:

Health-related quality of life differences between males and females (all participants, DBS and Non-DBS combined):

- When considering all of the participants (regardless of whether or not the participants had DBS), there **was a difference** between men and women's rating of health-related quality of life, with men reporting higher levels of health-related quality of life (perceived fewer difficulties in most of the domains assessed) when compared to women in this study.

- There **were significant differences** between men and women on 5 of the 8 domains, including Mobility, Emotional Well-being, Social Support, Communication, and Bodily Discomfort, with men reporting higher levels of health-related quality of life in all domains with exception to Communication, where woman had better ratings (see Figure 4).

- There **were no differences** between men and women's perception of health-related quality of life/level of difficulties on the domains of Activities of Daily Living, Stigma, and Cognitions.

![Figure 4. Gender Differences on The Parkinson's Disease Questionnaire (PDQ-39):](image)

Differences between males in the DBS group and Non-DBS group:

- There **were significant differences** between men who were in the **DBS group** versus the **Non-DBS group**, with men in the **DBS group** having more difficulties/lower levels of overall health-related quality of life.

- The difference in health-related quality of life was found on 3 of the 8 domains, including Mobility, Social Support, and Communication, with the **DBS group** having **lower levels** of health-related quality of life on these respective domains.

- The men in the **DBS group** and **Non-DBS group** had comparable health-related quality of life/difficulty on the domains of Activities of Daily Living, Emotional Well-being, Stigma, Cognitions, and Bodily Discomfort.
**Differences between females in the DBS group and Non-DBS group:**

- There was not a significant difference on overall health-related quality of life between women who were in the DBS group and the Non-DBS group.
- There were, however, significant differences between women in the DBS group and the Non-DBS group on 2 of the 8 domains, including Communication and Cognition. Specifically, the DBS group had better ratings of cognition and worse ratings on communication when compared to the Non-DBS group.
- The women in the DBS group and Non-DBS group had comparable health-related quality of life in the domains of Activities of Daily Living, Emotional Well-being, Stigma, Social Support, and Bodily Discomfort.

**Other Demographic Variables:**

- When looking at other demographic variables, including marital status, living alone/with someone, and education levels, there was only a significant difference in health-related quality of life in the domain of Social Support as it relates to those who live alone versus those who live with someone.
- Those individuals who live alone had worse ratings of Social Support as compared to those who live with someone.

**Younger Versus Older PD Groups:**

To look closer at the influence of age as it relates to attitude and health-related quality of life, the participants were divided into a “Younger PD group” and an “Older PD group”, 50 to 69 years and 70 years and older, respectively.

**Attitude:**

- When looking at all of the participants in the Younger PD group and Older PD groups, regardless of whether they had DBS or not, there was not a significant difference in attitude (positive or negative) between the two groups.
- The majority of both groups had high ratings of positive attitude and low ratings of negative attitude. The average rating of positive attitude fell between “Often” and “Always” having a positive attitude as it relates to their ability to face the challenges related to PD.
- Similarly, when looking at the DBS group and Non-DBS group within the Younger and the Older groups, there was no significant difference in attitude.

**Health-Related Quality of life for the Younger PD group with and without DBS:**

- There was not a significant difference between the DBS group and the Non-DBS group on overall health-related quality of life.
- There was, however, a difference on 2 of the 8 domains of health-related quality of life, including Mobility and Communication. Specifically, in the Younger PD group, the DBS group reported greater levels of difficulty with Mobility and Communication when compared to the Non-DBS group.
- The DBS group and Non-DBS group had comparable health-related quality of life/difficulty ratings on the domains of Activities of Daily Living, Emotional Well-being, Stigma, Social Support, Cognitions, and Bodily Discomfort.
Health-Related Quality of life for the Older PD group with and without DBS:

- There was not a significant difference between the DBS group and the Non-DBS group within the Older PD group on overall health-related quality of life.
- Similar to the Younger PD group, there was, however, a difference on 2 of the 8 domains of health-related quality of life, including Mobility and Communication. In the Older PD group, the DBS group had higher ratings of difficulty in these domains when compared to the Non-DBS group.
- The DBS group and Non-DBS group had comparable health-related quality of life/difficulty ratings on the domains of Activities of Daily Living, Emotional Well-being, Stigma, Social Support, Cognitions, and Bodily Discomfort.

Early Versus Advanced PD:

To look closer at the influence of disease duration on attitude and health-related quality of life, the participants in this study were divided into the groups “Early PD group” and “Advanced PD group.” Previous research has found that in PD the average time from symptom onset to development of motor complications was 6 years. Based on previous research, the participants in this study were divided into the groups Early versus Advanced PD, <6 years and 6+ years, respectively, to define a valid partition between early and advanced disease states.

Attitude:

- When looking at all of the participants in the Early and Advanced PD groups, regardless of whether they had DBS or not, there was not a significant difference in attitude (positive or negative) between the two groups.
- The majority of both groups had high ratings of positive attitude and low ratings of negative attitude. The average rating of positive attitude fell between “Often” and “Always” having a positive attitude as it relates to their ability to face the challenges related to PD.
- The DBS group did not have enough individuals in the Early PD group to look at similarities or differences in attitude between the Early (n=5) and Advanced PD group (n=224).
- For the Non-DBS group, there was no significant difference in attitude between the Early and Advanced PD group, with the majority of both groups having a positive attitude.

Health-Related Quality of life for the Early and Advanced PD groups:

- There was a significant difference between the Early PD group and Advanced PD group on overall health-related quality of life/difficulty rating. The Early PD group had a higher rating of overall health-related quality of life (fewer difficulties) when compared to the Advanced PD group.
- The Advanced PD group rated worse health-related quality of life/difficulty on 3 of the 8 domains when compared to the Early PD group, including Mobility, Activities of Daily Living, and Communication.
- The Early PD group and Advanced PD group had comparable health-related quality of life/difficulty levels on the domains of Emotional Well-being, Stigma, Social Support, Cognitions, and Bodily Discomfort.
Health-Related Quality of Life Over Time:

There was a subgroup of 79 participants who completed the health-related quality of life survey in 2007 and 2011. Thus, we were able to analyze the perception of health-related quality of life over time. Some of the general characteristics of the individuals who participated in both surveys can be found in Table 2.

### Table 2. Demographics and Clinical Features of the 79 Participants who Completed the 2007 and 2011 Surveys

<table>
<thead>
<tr>
<th>Variable</th>
<th>DBS (N=51)</th>
<th>Non-DBS (N=28)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean Age (Years)</td>
<td>66</td>
<td>69</td>
</tr>
<tr>
<td>Duration of PD (Years)</td>
<td>19</td>
<td>13</td>
</tr>
<tr>
<td>Mean age of PD Diagnosis (Years)</td>
<td>47</td>
<td>56</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>55%</td>
<td>57%</td>
</tr>
<tr>
<td>Female</td>
<td>45%</td>
<td>43%</td>
</tr>
<tr>
<td>Living with Someone</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>82%</td>
<td>86%</td>
</tr>
<tr>
<td>No</td>
<td>18%</td>
<td>14%</td>
</tr>
</tbody>
</table>
Positive Versus Negative Attitude:

- When looking at positive attitude, the participants as a whole did not show a change from 2007 to 2011, and the majority of participants maintained a positive attitude as it relates to their ability to face the challenges related to PD. The average rating of positive attitude was between “Often” and “Always” having a positive attitude (for both 2007 and 2011).

- As for negative attitude, there was a clinically significant finding reflecting a change in negative attitude. Specifically, there were significantly more individuals endorsing increased negative attitude in 2011 when compared to 2007. Moreover, there was an increase in intensity and frequency of negative thoughts related to the ability to cope with PD. For example, in 2007, only 11% indicated that they “often” thought PD was winning and only 1% reported that they “always” thought that PD was winning. In contrast, in 2011, 65% reported that they “often” think PD is winning and 27% reported that they “always” think that PD was winning.

Health-Related Quality of Life – Parkinson’s Disease Questionnaire-39 (PDQ-39):

- The overall health-related quality of life based on the PDQ-39 Single Index (total scale) did not reveal a significant change in perceived difficulty over time. Moreover, when comparing the total score on the PDQ-39 in 2007 to 2011, the scores were comparable. Note that lower scores reflect a better rating of health-related quality of life (0=best rating, no problem at all; 100=worst rating, always having difficulties with the symptoms assessed).

- When looking at specific domains on the PDQ-39, Mobility (the ability to get around) was the only domain reported that revealed clinically significant worsening over time (score of Mobility in 2007 = 36; score of Mobility in 2011=44, with higher scores reflecting increased difficulties). The other domains, including Activities of Daily Living, Emotional Well-being, Stigma, Social Support, Cognitions, Communication, and Bodily Discomfort, did not reveal statistically significant differences over time.

- To look closer at the influence of age as it relates to attitude and health-related quality of life, the participants were divided into a “Younger PD group” and an “Older PD group”, 50 to 69 years and 70 years and older, respectively. There was not a significant difference between the Younger group (n=49) and the Older group (n=30) on attitude or overall health-related quality of life.
Conclusions

Individuals with PD are confronted with physical, psychological, and psychosocial issues that impact quality of life. The medical community is increasingly recognizing health-related quality of life as a major criterion in evaluation of health interventions. The results of this study investigating health-related quality of life in individuals with and without DBS are discussed below in the context of the main objectives of this report.

1. **We examined the characteristics of health-related quality of life in 587 People with Parkinson’s (PWP) using the Parkinson’s Disease Questionnaire – 39 (PDQ-39), particularly as it relates to those who have undergone DBS (DBS group) and those who have not had DBS (Non-DBS group).**

   • There were significant differences between the **DBS group** and **Non-DBS group** in two of eight domains: Mobility (ability to get around) and Communication, reflecting that the **DBS group** had greater difficulties with these functions.

      ° Research studies have found that DBS therapy does not help or may even adversely affect balance (consequently impacting the ability to get around) and speech (communication)\(^8,9,10\). Thus, the findings in this study also reflect the possibility that DBS therapy may have an undesirable impact on these domains. Other domains between these two groups were comparable, which is an expected finding; DBS therapy is designed to improve some motor symptoms (e.g., tremor; rigidity), which are not directly evaluated with the use of the PDQ-39.

      ° The implications of these findings are clear. Further and continued attention to and intervention for mobility (i.e., the ability to get around) and language/communication functions in individuals with PD is warranted, particularly as it relates to the impact of DBS therapy on these symptoms. Increasing the utilization of a multi-disciplinary treatment approach (e.g., utilizing physical therapists and speech therapists) for patient care may facilitate improved functionality and quality of life.

   • When looking at **Early** versus **Advanced PD** based on disease duration, the **Advanced PD group** reported greater difficulties with mobility, completion of basic activities of daily living (e.g., washing self; dressing self), and communication.

      ° These findings are also consistent with the literature\(^11,12\). As PD progresses, increased difficulty with mobility, the completion of activities of daily living, and communication are common experiences for many individuals.

      ° These findings support the need for intervention over time (e.g., intermittent exposure to clinicians specializing in “rehabilitation”, such as physical therapists, occupational therapists, and speech therapists).

   • Gender differences were apparent in health-related quality of life. Women reported worse health-related quality of life when compared to men.

      ° This finding is consistent with gender differences in quality of life in other medical populations, such as patients with cardiac disease and stroke, where women reported lower levels of quality of life when compared to men\(^13,14,15,16\). Women who report poorer quality of life than men may have poorer psychosocial adjustment to their medical condition, particularly as it relates to their functional limitations, and differences in quality of life may also be related to biological differences between men and women.
This finding is another reminder that demographic and individual factors are important to take into consideration when determining therapies and interventions for PWP. Individualized therapies (e.g. rehabilitation programs; social, occupational, and/or psychological therapy; etc.) should be tailored for each individual to best optimize adaptation and quality of life.\textsuperscript{2,14}

Future studies are needed to further examine gender differences in psychosocial adjustment for individuals with PD.

2. **We examined “attitude” with PWP.**

   - Generally, regardless of whether an individual was in the DBS or Non-DBS group, and whether or not they were in the Younger or Older group and in the Early or Advanced PD group, individuals in this study had a generally positive attitude in the face of their daily challenges with PD. A minority of individuals also endorsed having a negative attitude as it relates to PD and what the condition portends for the future.

3. **We examined QOL and attitude over time in individuals with PD who have and have not undergone DBS therapy.**

   - Over a 4-year period, mobility (e.g., difficulty getting around) was the only variable on the PDQ-39 to be reported as having significantly worsened over time. Other domains related to health-related quality of life were not statistically significant over the 4-year period.
   
   - When looking at attitude, the majority of individuals continue to maintain a positive attitude. That being said, however, there was a significant increase in intensity of negativity attitude and in the number of individuals experiencing a negative attitude. Specifically, as time progressed, individuals increasingly felt that PD was “winning,” and dwelling on the difficulties related to PD became more prevalent.

   - Greater attention toward attitude in individuals with PD is warranted, as attitude is strongly related with general quality of life and emotional well-being. For clinicians and carers, understanding how an individual with PD is adapting to his or her medical condition over time may help facilitate better intervention for his or her overall well-being.

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**Acknowledgements**

As we complete our 11\textsuperscript{th} DBS-STN patient survey, I want to express my gratitude to all those who participated in this study and to the many carers without whom our lives would not be as meaningful. I want to extend my appreciation to Dr. Jeffrey C. Wertheimer, our Chief Research Consultant and a Clinical Neuropsychologist at Cedars-Sinai Medical Center, California, who analyzes the data and adds his professional skills to our work. I want to thank Weiming Tang, a doctoral student in the Department of Epidemiology at the University of California, Los Angeles, for his assistance with data analysis. I would like to thank Dr. Michele Tagliati, the Vice Chair of Neurology and the Director of the Movement Disorders Program at Cedars-Sinai Medical Center, California, and the scientific and medical director for The Parkinson Alliance, for his editorial contributions to this manuscript. Additionally, I want to thank Aurore Duboille, Executive Assistant at The Parkinson Alliance, for her assistance with database management, and I want to acknowledge the ongoing dedication and tenacity of Carol Walton, Chief Executive Officer for The Parkinson Alliance, who assists, at many levels, in making this research possible.

Margaret Tuchman  
President  
The Parkinson Alliance
References


