

## Differential Impact of Coping Styles on Quality of Life for Individuals with Parkinson's Disease with and without DBS

### INTRODUCTION

Individuals with Parkinson's disease (PD) are faced with the challenge of coping with a chronic, progressive disease that will alter their lives in numerous ways.<sup>1</sup> Understanding coping reactions and strategies and its impact on quality of life is an area of great importance for patients, family members, and physicians. How an individual copes with specific stressful symptoms of the disease has a significant effect on overall function and well-being.

- There are numerous ways that individuals cope with medical illness, and research has found that some ways of coping may be more beneficial than other ways.
  - Research on coping with PD has shown that patients who cope best use problem-focused coping for management of symptoms and emotional-focused coping for living with the stress of being a patient with PD.<sup>2,3</sup>
  - Some research has highlighted three main types of coping.<sup>2</sup>
    - **Active Coping** (e.g., I take additional action to try to get rid of the problem; I consult others who have had similar problems about what they did)
    - **Emotional Regulation** (e.g., I talk to someone about how I feel; I learn to accept and live with it; I get upset and let my emotions out)
    - **Distancing** (I seek God's help; I refuse to believe it has happened; I turn to other activities to take my mind off things)
  - Other literature has pointed out that maintaining a positive attitude, optimism, and happiness can lead to longer lives, less disability, and increased quality of life.<sup>4</sup>
  - Frazier and Marsh encourage individuals to regard PD obstacles as challenges to be overcome, rather than hopeless barriers.<sup>1</sup> They indicated that a positive approach allows for a sense of pride, control, and hopefulness that can lead to more effective coping.

When considering the complexity of PD, particularly as it relates to the fluctuating changes of the symptoms, understanding the benefit of specific coping strategies on overall function and quality of life is of great importance.

### OBJECTIVE

Although there has been some research on coping with PD, further understanding about the coping strategies and its implications on quality of life is warranted. The goal of this project was to learn more about coping strategies/mechanisms (the way people cope with illness) in individuals with Parkinson's disease who have and have not undergone DBS-STN, and to study the relationship between coping, Quality of Life, and certain patient variables.

## METHODS

The participants were recruited from a variety of sources. Some had participated in 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](http://www.parkinsonalliance.org)), or our affiliate website devoted to DBS ([www.dbs-stn.org](http://www.dbs-stn.org)). Participants came from around the United States, Canada, France, South Africa, and the UK. The participants in this report included 85 individuals with PD who underwent DBS and 90 individuals with PD without DBS.

The participants in this study completed a demographics questionnaire, the Coping with Health Injuries and Problems (CHIP), and the Parkinson's Disease Questionnaire-39 (PDQ-39) each of which will be explained below.

### **The Demographic Questionnaire:**

The demographic questionnaire included questions related to background information of the participants as well as questions related to having a positive vs. negative attitude. Some examples of the statements related to having a positive attitude include: "I treat the symptoms of PD as a challenge that I will readily overcome", "I believe that if I maintain a positive attitude that I will have less stress and a better chance of dealing with PD", "Even when I have worsening of my PD, I can create positive change within my life." Some examples of the negative statements include: "If I receive bad news from my physician I am likely to say 'that's it, I may as well not try anymore'", "I tend to dwell on all of the failures of all the treatment they have tried for my PD", and "I feel as though PD is winning and I am losing."

### **Coping with Health Injuries and Problems (CHIP):**

The CHIP is a 32-item, multi-dimensional coping measure.<sup>5</sup> It probes the following coping techniques: Distraction, Palliative, Instrumental, and Emotional Preoccupation.

1. **Distraction:** Describes the extent to which the respondent uses actions and thoughts that are aimed at avoiding preoccupation with the health problem. This involves thinking about other, usually more pleasant experiences, engaging in unrelated activities, and being in the company of others (e.g. generally distracting themselves from the problems).
2. **Palliative:** Describes the various "self-help" responses utilized to alleviate the unpleasantness of the situation. This type of coping response includes attempts at feeling better through, for example, making one-self comfortable by changing the surroundings, getting plenty of rest, etc. These responses tend to be a more passive approach to coping.
3. **Instrumental:** Focuses on various "Task-Oriented" strategies used to deal with illness. Such coping strategies can be categorized as active or problem-focused because they indicate that the individual is seeking help for the illness or trying to learn more about it.
4. **Emotional Preoccupation:** Involves the extent to which an individual focuses on the emotional consequences of the health problem. These coping behaviors are related to "Emotion-Oriented" coping, and include responses like self-preoccupation and fantasizing.

### **The Parkinson’s Disease Questionnaire (PDQ-39):**

The PDQ-39 has 39 items.<sup>6</sup> Higher scores reflect lower Health Related Quality of Life (HRQoL). The PDQ-39 has eight subscales: mobility, activities of daily living, emotional well-being, stigma, social support, cognitions, communication, and bodily discomfort. Items in each subscale, as well as in the total scale, can be summarized into a total score out of 100 possible points.

## **RESULTS**

The summary of the demographic information for this study can be found in Table 1. The average age of PD onset was 46 years for the **DBS group** and 54 years for the **Non-DBS group**. Male and female participants were equally represented for each group and most of the patients were married. The **DBS group** had an earlier age of onset of PD and had longer duration of PD than the **Non-DBS group**.

**Table 1. Demographics and clinical features of the sample.**

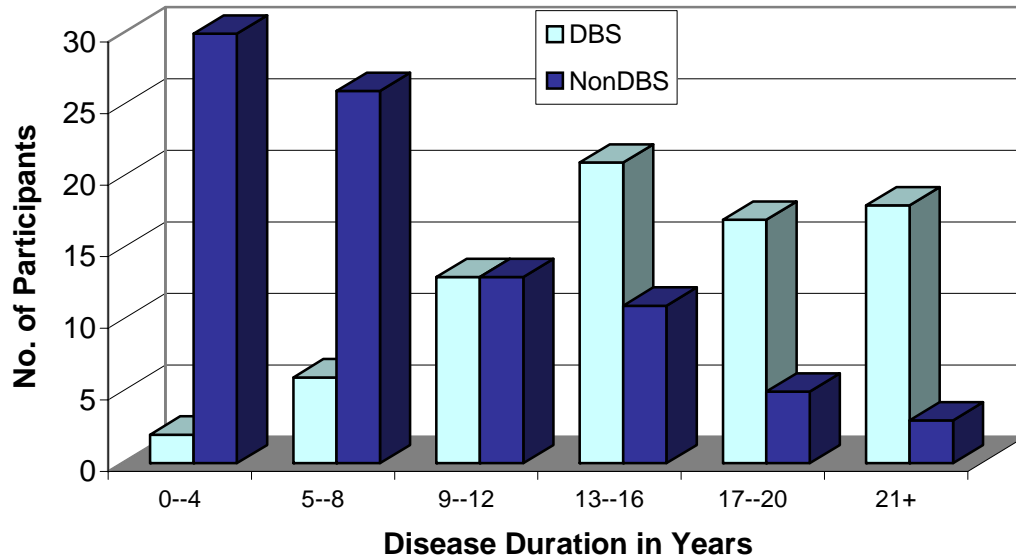
<b>Variable</b>	<b>DBS (n=85)</b>	<b>Non-DBS (n=90)</b>
Mean Age in years	62	63
Duration of PD in years *	16.0	8.8
Percent Male	53%	60%
Percent Female	47%	40%
Percent Married	67%	69%
Mean Age of PD onset (in years)*	46	54
Age at Time of DBS	58	n/a
Average Time since DBS-STN (in years)	4.1	n/a

\* denotes significant differences between the groups

### ***Duration of PD within the two groups:***

There was a significant difference in duration of PD between the two groups (**DBS>Non-DBS**; see Figure 1). For research purposes it is important to take duration of PD into consideration, which was done for all of the results reported below.

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



**Coping with Health Injuries and Problems (CHIP):**

*For purposes of this study, interpretation of the CHIP was broken down into three categories: Below Average, Average, and Above Average. **Below Average** scores reflect that individuals use that coping strategy less than the general population. **Average** scores reflect a coping strategy that is used as often as the general population. **High Average** scores reflect a coping style that is used more than the general population.*

- When assessing the coping strategies between the **DBS group** and the **Non-DBS group**, there were no statistically significant differences between the groups as it related to their coping styles (see Table 2 at the end of the report). The coping styles/strategies include:
  - **Distraction** (using actions and thoughts to avoid preoccupation with health problems)
  - **Palliative** (a more passive approach to coping, such as finding comfortable surroundings)
  - **Instrumental** (a proactive, task-oriented approach)
  - **Emotional Preoccupation** (to focusing on emotional factors related to their health problems)
- In fact, the coping strategies for both groups were very similar. As a whole, for the majority of the participants in this study, individuals fell in the average to above average range in both groups for three of the four coping strategies. These strategies included distraction techniques, task-oriented techniques, and emotional preoccupation. This finding reflects that the participants in this study tend to use these strategies as often as or even more than the general population.
- In contrast, for the majority of the participants in this study, their use of more passive, self-comforting coping techniques (the Palliative approach) fell in the below average range, which reflects that they use that strategy less often than the general population.
- In summary, the majority of the participants in this study **did not** tend to use a more passive, comfort-seeking approach. They tended to **use** methods that were related to more active coping strategies (such as distracting one’s self from their problems or actively seeking help for their problems) and that are related to focusing on emotional consequences related to their health problems.

### Positive Attitude:

A series of questions were asked regarding how individuals cope with different types of adversity as it relates to their symptoms of PD, and there were no significant differences between groups on these questions. More specifically, when the questions were broken into negative versus positive attitudes in the context of coping with their difficulties, there was no difference between the groups, meaning that one group did not tend to use either a positive or negative attitude more than the other group.

### Parkinson’s Disease Questionnaire-39:

The summary of the PDQ-39 information for this study can be found in Table 3. The **DBS group** endorsed a lower rating of quality of life than the **Non-DBS group** as it relates to difficulties with Mobility. Specific mobility differences were noted in regard to carrying shopping bags, walking distances, getting around the home and public, requiring someone to accompany them when going out, and feeling more confined to one’s home. Additionally, the two groups were significantly different on the Communication scale. The **DBS group**, when compared to the **Non-DBS group**, reported lower levels of quality of life as it relates to difficulties with speech, inability to communicate properly, and feeling ignored by people. The **DBS group** also had a higher PDQ39 score suggesting that, as a whole, they reported lower levels of quality of life than the **Non-DBS group**. It should be noted, however, that the two domains Mobility and Communication appeared to account for the difference in the overall rating of Quality of Life between the two groups.

Gender differences were found in one’s quality of life, regardless of whether one had DBS or not. Men were found to report higher quality of life than did the women. There were no significant differences between ethnic groups, marital status, living alone/with someone, or education in regard to quality of life or type of coping strategy used. There was a significant finding when looking at individuals who were separated and living alone when compared to those who were living with someone. Specifically, those who were separated and living alone reported lower levels of quality of life when compared to those who were living with someone.

**Table 3. The Parkinson’s Disease Questionnaire (PDQ-39):**

Variable	DBS (n=85)	Non-DBS (n=90)
PDQ Mobility*	45	33
PDQ Activities of Daily Living	33	28
PDQ Emotional Well Being	31	30
PDQ Stigma	17	19
PDQ Social Support	24	18
PDQ Cognitive Impairment	29	29
PDQ Communication*	47	27
PDQ Bodily Discomfort	38	40
PDQ Single Index*	33	28

- \* Denotes significant differences between the groups
- Higher scores reflect lower Health Related Quality of Life

## Coping and Quality of Life:

Coping styles were significantly related to quality of life. Across quality of life domains (Mobility, Activities of Daily Living, Emotional Well-Being, Stigma, Social Support, Cognitive Impairment, Communication, Bodily Discomfort, and Overall Quality of Life), a predominant theme was that distraction and task-oriented coping techniques were related to reports of higher levels of quality of life. Conversely, individuals who were emotionally preoccupied or who used passive, comfort-seeking coping techniques were negatively related to quality of life. In other words, people who were emotionally preoccupied or those who used a more passive approach to coping tended to report lower levels of quality of life.

When looking at the four main coping techniques (1. distraction techniques, 2. passive, self-comforting techniques, 3. pro-active, task-oriented techniques, and 4. being emotionally preoccupied), this study found that the use of pro-active, task-oriented approaches to coping had the strongest relationship to higher ratings of quality of life, whereas the emotionally preoccupied approach to coping had the strongest relationship to lower ratings of quality of life.

Further still, above all other variables that relate to quality of life, a positive attitude had the strongest relationship to higher ratings of quality of life.

## DISCUSSION

- Coping strategies do have a direct impact on quality of life in individuals in PD. More active strategies, such as using task-oriented strategies (being proactive about coping with their illness) and maintaining a positive attitude lead to higher ratings of quality of life than those who approach coping through being emotionally pre-occupied or using a passive, self-comforting approach.
- Maintaining a positive attitude and healthy expectations can have the greatest impact on quality of life than any other coping mechanism.
- These findings are consistent with other reports that active coping and positive attitudes have a positive impact on quality of life as it relates to people who have PD.<sup>1</sup>
- Some research has found that emotional regulation is helpful in coping with PD. It is important to highlight that emotional regulation appears to be related to healthy ways to cope with emotional distress by managing your emotions (e.g., I talk to someone about how I feel; I learn to accept and live with it). Our study found that emotional pre-occupation can lead to lower levels of quality of life. Moreover, emotional preoccupation appears to be a poor way of coping with illness, and it has an adverse impact on overall quality of life. Emotional pre-occupation differs from emotional regulation in that emotional pre-occupation relates to being focused on your emotional state without management of your emotions. Thus, in the context of other research<sup>2</sup>, it can be deduced that more active strategies of coping with emotional discomfort can lead to higher levels of quality of life, whereas simply being pre-occupied with emotional discomfort can lead to lower ratings of quality of life.
- The **DBS group** endorsed a lower rating of quality of life than the **Non-DBS group** as it relates to difficulties with Mobility and Communication. Otherwise, there were no differences between the groups' quality of life ratings as it related to Activities of Daily Living, Emotional Well-Being, Stigma, Social Support, Cognitive Impairment, and Bodily Discomfort.

- In regard to mobility and communication difficulties causing reduced quality of life within PWP and DBS, it is clear that focus needs to be placed in these areas in research, clinics, and other treatment settings. Our team has listened to PWP and found that many individuals with DBS experience debilitating speech disturbances from the device that improves many other areas of their lives. Specific speech therapies and training have been used to minimize the effect of this symptom on the PWP's quality of life, but it is clear from this research that the problem continues and deserves additional attention from clinicians as well as researchers if we are to improve quality of life for these individuals.
- We found some demographic and gender differences in our study suggesting that attention needs to be paid in those areas as well. These individual factors are very important to take into consideration when determining therapies and interventions for PWP. Individualized therapies (e.g. social, occupational, or psychological) should be tailored for each PWP to best optimize one's quality of life.
- Our finding regarding the relationship between higher reports of quality of life and positive expectations needs to be addressed from a team approach. Everyone involved with the care of the PWP can encourage and promote positive expectations for not only the patient but for the carers as well. Reframing situations, looking for the positive, using a strength-based philosophy, and encouraging active, task-oriented coping strategies will be beneficial for patients with PD, particularly in the context of improving quality of life. It will also be important to instill these approaches while providing realistic expectations in one's challenges with this disease.
- The implications of the data also point to the benefit of clinicians using sound questionnaires to obtain a clear understanding about the way individuals tend to cope with their health problems. They can integrate the conceptualization of their patient's coping strategies into treatment, either by encouraging healthy, adaptive coping mechanisms or intervening when individuals use coping strategies that are less effective or that even have an adverse impact on his or her quality of life.

### **ACKNOWLEDGEMENTS**

As we complete our eighth DBS-STN patient survey, I want to express my gratitude to two People with Parkinson's (PWP), Richard Kramer, who also had DBS, and John Wherry, for their assistance with the writing of this report. Their input and data analysis is very important to our work. We also have two Neuropsychologists who analyze the data and add their professional skills to our work, including Dr. Jeffrey C. Wertheimer, staff Neuropsychologist for Brooks Rehabilitation Hospital, and Dr. Julie Smith, staff Neuropsychologist for the VA Illiana Health Care System. 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 data entry, and I want to acknowledge the ongoing dedication and tenacity of Carol Walton, Chief Executive Officer for The Parkinson Alliance.

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

**Table 2. Coping with Health Injuries and Problems (CHIP)**

Coping Mechanism	DBS Group (n=81)	Non-DBS Group (n=90)
<b>Distraction:</b> using actions and thoughts to avoid preoccupation with health problems		
Below Average	25%	27%
Average	36%	34%
Above Average	39%	39%
<b>Palliative:</b> more passive, self-comforting coping techniques		
Below Average	54%	57%
Average	31%	29%
Above Average	15%	14%
<b>Instrumental:</b> active or task-oriented techniques such as seeking help for and education about the illness		
Below Average	27%	12%
Average	36%	49%
Above Average	37%	39%
<b>Emotional Preoccupation:</b> self-preoccupation; focusing on emotional factors related to their problems		
Below Average	32%	31%
Average	34%	22%
Above Average	36%	47%

**Below Average** scores reflect that individuals use the coping strategy less than the general population.

**Average** scores reflect a coping strategy that is used as often as the general population.

**High Average** scores reflect a coping style that is used more than the general population.

- **Distraction techniques:** The majority of the participants in this study either used distraction techniques **as much as or more than** the general population.
- **Palliative techniques:** The majority of the participants in this study tended to use passive, self-comforting coping strategies **less than** the general population. Additionally, when compared to the other three coping strategies, the majority participants in this study did not use this coping strategy as much as they do the other three approaches to coping.
- **Instrumental techniques:** The majority of the participants in this study tended to use active, task-oriented techniques **as much as or more than** the general population.
- **Emotional Preoccupation:** The majority of the participants in this study focused on emotional factors related to their problems **as much as or more than** the general population. When looking at the **Non-DBS group**, a large percentage of these participants are focused on the emotional factors related to their problems, more so than the general population.



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