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Improving the Quality of Life
in the Parkinson's Community

**Resilience in Individuals
with Parkinson's Disease
with and without
Deep Brain Stimulation**

Spring 2013

INTRODUCTION

Individuals with Parkinson's disease (PD) experience a number of motor and non-motor symptoms that can cause distress and reduce quality of life. In that context, individuals with Parkinson's, family members, and treatment providers alike, commonly think of the debilitating symptoms and the adverse impact the symptoms have on day-to-day function, relationships, and community involvement, the next attempt for medical intervention, and what the future holds. The ongoing changes in functional skills and living with the uncertainty that comes along with PD can lead to significant adjustment difficulties, symptoms of depression and anxiety, and a wavering sense of self.

Less common are conversations pertaining to PD that highlight a person's strengths and the resilience that is necessary to persevere through the challenges of living with PD (e.g., debilitating symptoms, thoughts about having a progressive and incurable illness, impact on social relationships, etc.). Resilience is a dynamic process whereby individuals cope with and exhibit positive behavioral adaptation to stress, challenge, and adversity. Research studies have demonstrated that resilience is composed of several elements, including, but not limited to, cognitive factors such as creativity, intelligence and maintaining perspective; personality characteristics such as having a positive/optimistic attitude; the tendency to resolve sources of depression and anxiety to maintain sound emotional well-being; and, social factors such as a belief of social support and sense of connectedness to the environment^{1,2,3,4}. Although there is literature discussing effective coping strategies for individuals with PD^{5,6,7}, there has been little research emphasizing the patient's perspective about resilience in the context of PD. One study, conducted by Robottom and colleagues⁸, found that resilience is significantly related to less disability, less apathy, depression, fatigue, and better physical and mental quality of life. Resilience was not associated with disease severity, however. The authors concluded that resilience seems to be more of a personality trait and is independent of physical function in PD and does not necessarily decrease over time as the severity of the disease worsens.

Obtaining a better understanding of the prevalence of and clinical characteristics related to resilience in people with Parkinson's would provide an opportunity to implement a strength-based intervention approach to enhance quality of life.

OBJECTIVES

1. To obtain the "patients' perspective" about their sense of resilience, and to better understand how resilience relates to other factors, such as attitude, self-confidence, emotional well-being, health-related quality of life, and quality of life in general.
2. To compare and contrast resilience and the factors related to resilience for **DBS** and **Non-DBS** patients in both a **Younger PD group** and **Older PD group**.
3. To investigate the relationship between **disease duration**, resilience, and factors related to resilience for **DBS** and **Non-DBS** patients.

METHODS

Participants were recruited from a variety of sources. Individuals were invited to participate in the current survey based on: (1) previous survey participation; (2) response to study announcements in medical clinics around the country; (3) participation in local PD support groups advertising the study; or (4) response to survey announcements on The Parkinson Alliance website (www.parkinsonalliance.org) or our affiliate website devoted to DBS (www.DBS4PD.org). There was a response rate of 29.4 percent; 2,807 surveys were disseminated between June and December 2012. The participants completed a paper-and-pencil survey comprised of the following questionnaires:

The Demographic Questionnaire and Questions Related to Resilience:

The demographic questionnaire included questions related to background information as well as questions related to a broad range of factors that may impact resilience. Specific factors that may impact resilience that were assessed in this report included attitude (optimism and pessimism), perceived quality of life, health-related quality of life, depression, and anxiety.

The Life Orientation Test (LOT)⁹:

The LOT is comprised of 10 questions, with 3 questions related to optimism, 3 questions related to pessimism, and 4 questions that are considered “filler” and are unrelated to optimism or pessimism. For this study, only the questions related to optimism and pessimism were used.

Questions related to Optimism:

- In uncertain times I usually expect the best.
- I'm always optimistic about my future.
- Overall, I expect more good things to happen to me than bad.

Questions related to Pessimism:

- If something can go wrong for me, it will.
- I hardly ever expect things to go my way.
- I rarely count on good things happening to me.

Each item is scored on a scale from 0 (strongly disagree) to 4 (strongly agree). A total score of 0 reflects extreme pessimism, and a total score of 24 reflects extreme optimism. On average, most people score 15, slightly optimistic.

The General Self-Efficacy Scale (GSE)¹⁰:

The GSE is comprised of 10 items inquiring about an individual's perceived self-confidence when faced with challenges or problems. For example, some statements include: “I can always manage to solve difficult problems if I try hard enough;” “I am confident that I could deal efficiently with unexpected events;” “I can remain calm when facing difficulties because I can rely on my coping abilities;” “I can usually handle whatever comes my way.” Each item is scored on a scale from 1 (not at all true) to 4 (exactly true). A sum of the 10 items is created to yield the final composite score. The composite score can range from 10 (low self-efficacy) to 40 (high self-efficacy).

State Trait Anxiety Inventory (STAI)¹¹:

The STAI is a self-report instrument that differentiates between the temporary condition of state anxiety and the longstanding quality of trait anxiety. The STAI consists of two scales containing 20 items each. One scale addresses “state anxiety” while the other scale addresses “trait anxiety.” “State anxiety” relates anxiety or stress that exists “right now.” “Trait anxiety” refers to a general feeling of the experience of stress or anxiety. Each item is scored on a scale from 1 (not at all) to 4 (very much so). Scores are summed, and the total score can range from 20 (absence of anxiety) to 80 (severe anxiety).

Parkinson's Disease Questionnaire – 8 (PDQ-8)^{12,13}:

The PDQ-8 is a PD-specific health-status questionnaire that is comprised of eight items. It was developed from the PDQ-39¹³, which has 39 questions, to decrease the burden for respondents. The eight items ask whether the individual has experienced the following symptoms in the past month because of having PD: embarrassment; difficulty with physical complaints (painful muscle cramps or pains); difficulty getting around in public places, dressing, and communicating; and problems with depression, close relationships, and concentration. Each item is scored on a scale from 0 (never or not at all) to 4 (always or cannot do at all). Scores are summed, and the total score can range from 0 (normal) to 32 (worse disability).

RESULTS

There were 825 individuals who participated in this survey, including 284 participants with PD who underwent DBS (**DBS group**) and 541 individuals with PD without DBS (**Non-DBS group**). Please see Table 1 for the demographic information and clinical characteristics of the participants. As shown in Table 1 and Figures 1 and 2, the **DBS group**, on average, was younger and had a longer duration of PD as compared to the **Non-DBS group**. Therefore, the data were analyzed separately by age group (younger, older) and duration of disease (early – PD less than 6 years, advanced 6-10 years, and advanced 11-plus years).

Table 1. Demographic and Clinical Characteristics of the Participants

	Total Sample (N=825)	DBS Group (N=284)	Non-DBS Group (N=541)
Average Age in Years * (Range; SD)	69 (39-94; 9.6)	66 (40-90; 8.7)	70 (39-94; 9.64)
Male	58%	62%	56%
Female	42%	38%	44%
Married	75%	76%	75%
Living with Someone	87%	88%	85%
PD Characteristics			
Average years since diagnosis (Range; SD)*	10 (0-44; 7.3)	15.3 (1-44; 7.12)	8 (0-36; 5.84)
Younger PD Group (50 to 69 years of age)*	49%	62%	42%
Older PD Group (70 plus years of age) *	48%	38%	58%
Early PD group (Disease Duration less than 6 years)*	31%	6%	44%
Advanced PD group 6-10 years *	27%	22%	30%
Advanced PD group 11 plus years *	42%	72%	26%
DBS Characteristics			
Average Age at Time of DBS in Years (Range; Standard Deviation)		61 (24-85; 9.21)	N/A
Average Duration since DBS in Years (Range; Standard Deviation)		5 (1-18; 3.92)	N/A
DBS Target			
Subthalamic Nucleus (STN)		88%	N/A
Globus Pallidus interna (GPi)		7%	N/A
Thalamus		5%	N/A
Bilateral Stimulation		87%	N/A
Unilateral Stimulation		13%	N/A

SD=Standard Deviation

* Denotes significant differences between the DBS and Non-DBS groups

Figure 1. Age Categories for DBS and Non-DBS groups

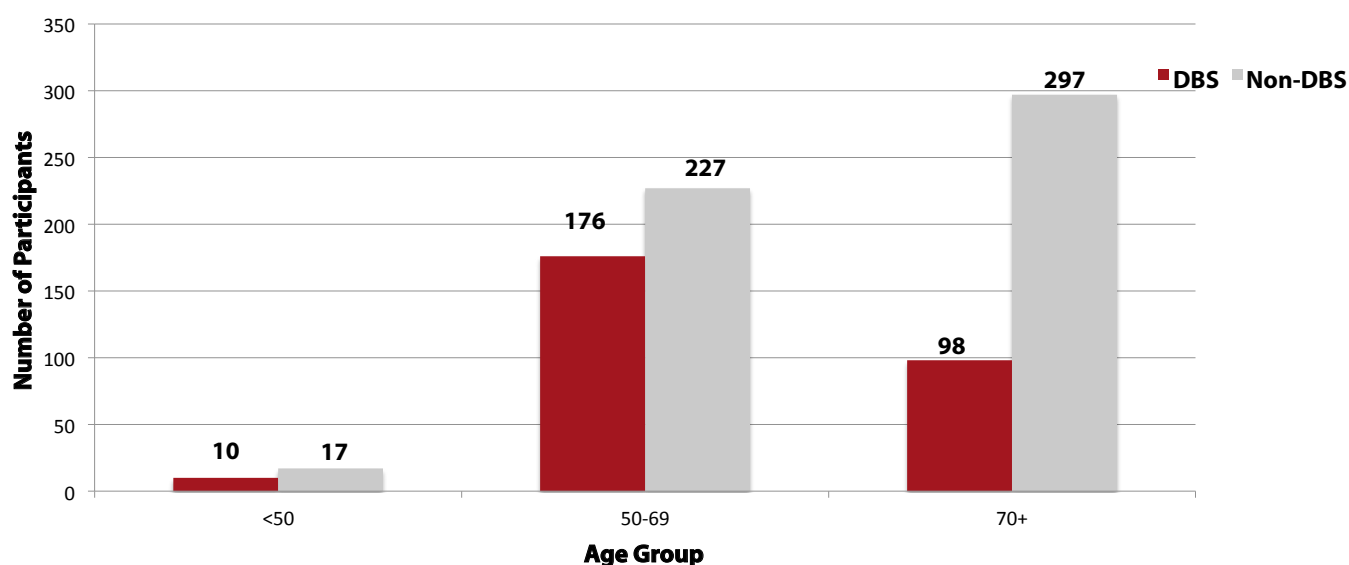
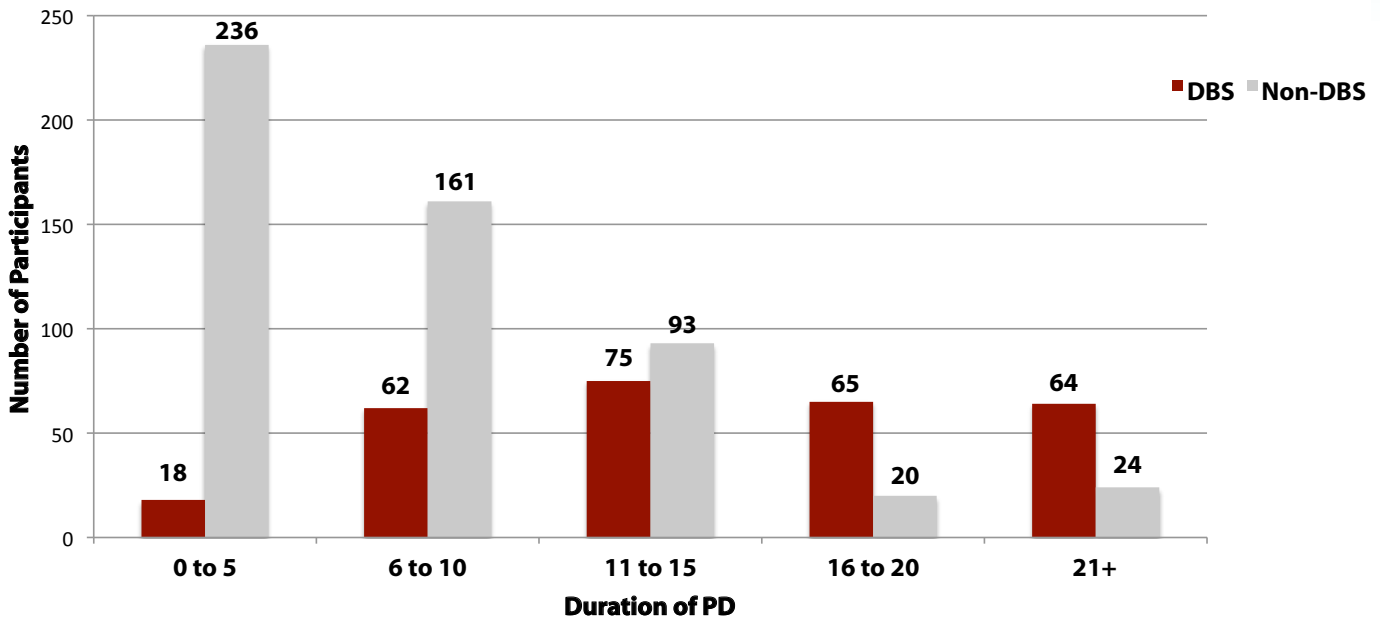


Figure 2. Disease Duration (in Years) for DBS and Non-DBS groups



Total Sample (825 participants)

Resilience, Attitude, Emotional Well-being, and Quality of Life

- 75% of the participants perceive themselves as either “often” or “always” **resilient**, with 23% perceiving themselves as “sometimes” resilient, and 2% reporting that they do not feel resilient at all.
- 69% of the participants rated their **quality of life** as good to excellent, with 27% reporting “fair” quality of life, 4% reporting “bad” quality of life, and <1% reporting that quality of life “could not be worse.”
- The participants’ responses on **The Life Orientation Test**, a measure of **optimism vs. pessimism**, indicated that the average rating for the participants was 15.80 (range = 0 to 24), which reflects that they are “slightly optimistic.”
- The average score on **The General Self-Efficacy Scale**, a measure of **self-confidence**, was 23.60 (range = 10 to 40), which reflects moderate levels of self-confidence when facing challenges or problems.
- On a question asking participants to rate their **depression**, 48% of the participants indicated that they experience mild levels of depression, while 21% reporting moderate levels of depression and 2% reporting severe levels of depression.
- On a question asking participants to rate their **anxiety**, 47% of the participants indicated that they experience mild levels of anxiety, while 28% reported moderate levels of anxiety and 4% reported severe levels of anxiety.
- On the State Trait Anxiety Inventory, the average score for “**state anxiety**” (anxiety “right now” [at the time of completing the survey]) was 36.24, which reflects that the average participant was not experiencing significant levels of anxiety.
 - 26% of the participants were experiencing significant levels of anxiety (at the time of completing the questionnaire).
- On the State Trait Anxiety Inventory, the average score for “**trait anxiety**” was 35.48, which reflects that the average participant does not experience significant levels of anxiety in general.
 - 31% of the participants were experiencing significant levels of general anxiety.
- Higher ratings of **resilience** and **self-confidence** were significantly related to better quality of life, more optimism, less pessimism, less health-related difficulties, less depression, and less anxiety.

- Higher ratings of **health-related quality of life** (PDQ-8) were significantly related to higher optimism, resilience, and self-confidence and less difficulties with depression, stigma and social support. PDQ-8 items included mobility, completing activities of daily living, depression, social support, cognition, speech, pain, and stigma.
 - The less disturbance with variables related to health-related quality of life, the greater the reported resilience and self-confidence.

Comparison of DBS versus Non-DBS groups

YOUNGER Participants (50-69 years of age; N=403) and OLDER Participants (70+ years of age; N=395): Matched on Disease Duration

- For both the **Younger PD group** and **Older PD group**, there were no differences between the **DBS** and **Non-DBS groups** as it relates to the level of optimism (Life Orientation Test), self-confidence (The General Self-efficacy Scale), resilience, quality of life, life satisfaction, depression (self-report depression rating), or anxiety (State Trait Anxiety Scale and a self-report anxiety rating).

Disease Duration: Early versus Advanced PD

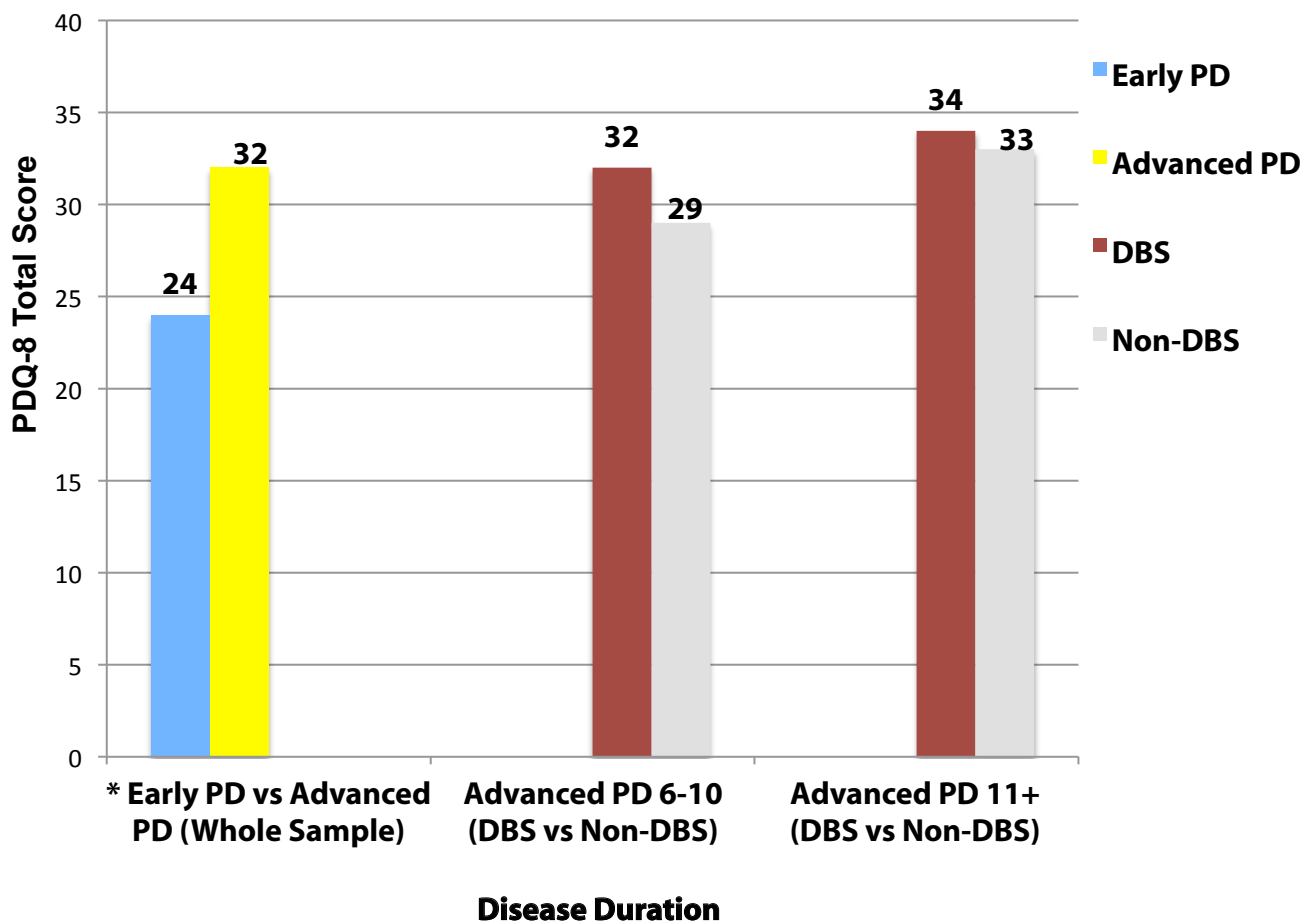
Previous research has found that in PD the average time from symptom onset to development of motor complications was 6 years (dyskinesias and motor fluctuations)^{14,15}. Thus, based on previous research, the participants in this study were divided into the groups **Early** versus **Advanced PD**, **<6 years** and **6+ years**, respectively, to define a valid partition between early and advanced disease states^{14,15}. To look at disease progression more closely, the **Advanced PD group** was divided into two groups, “**Advanced PD 6 -10 years**” and “**Advanced PD 11+ years.**”

DBS and **Non-DBS** participants could not be compared in the “**Early PD group**,” as there are too few individuals in the **DBS group** who are within the “**Early PD group**” (**DBS**: N=18; **Non-DBS**: N=236; see Figure 2). The small number of individuals with **DBS** in the **Early PD group** can be explained by DBS candidacy standards. Moreover, several of the world experts in DBS therapy for PD patients convened in 2009 to establish an “Expert Consensus and Review of Key Issues” related to DBS for PD. This group of individuals indicated that DBS therapy is most commonly offered as a treatment intervention after an individual has had PD for more than 5 years¹⁶. It is worth mentioning, however, that a recent clinical trial has identified some potential clinical benefit of receiving DBS therapy at an early stage of PD (within 5 years of PD diagnosis;¹⁷). Nonetheless, due to the small number of **DBS** participants in the **Early PD group** in this study, analyses comparing **DBS** versus **Non-DBS** participants in the **Early PD** group were not conducted.

- The **Early PD group** responses on the PDQ-8 revealed better **health-related quality of life** than the **Advanced PD group**. (See Figure 3)
- **Health-related quality of life** ratings were not significantly different between the **DBS** and **Non-DBS groups** within the **Advanced PD 6-10 years group** and the **Advanced PD 11+ years group**. (See Figure 3)
- The **Early PD group** had modestly higher ratings of **positive attitude** (Life Orientation Test; average score = 16.5) when compared to the **Advanced PD group** (Life Orientation Test; average score = 15.5).
- The **Early PD group** had modestly higher ratings of **self-confidence** (The General Self-efficacy Scale; average score = 24.6) when compared to the **Advanced PD group** (The General Self-efficacy Scale; average score = 23.2).
- There was not a statistically significant difference between the **Advanced PD 6-10 years group** and the **Advanced PD 11+ years group** as it related to **positive attitude** (Life Orientation Test; average score = 15.3 and 15.6 for **PD 6-10 years** and **PD 11+ years**, respectively).

- There was not a statistically significant difference between the **Advanced PD 6-10 years group** and the **Advanced PD 11+ years group** as it related to **self-confidence** (The General Self-efficacy Scale; average score = 23.0 and 23.3, PD 6-10 years and PD 11+ years, respectively).
- The **Early PD group** had slightly higher ratings of **quality of life** when compared to the **Advanced PD group**. (See Table 2)
- There was not a significant difference in **quality of life** ratings between the groups **Advanced PD 6-10 years** and **Advanced PD 11+ years**. (See Table 2)
- Perceived **resilience** was significantly different between the **Early PD group** and the **Advanced PD group**. There was not a statistically significant difference in ratings of resilience between the groups **Advanced PD 6-10 years** and **Advanced PD 11+ years**. (See Table 3)
- As for emotional well-being, there were no differences between the **Early PD group** and the **Advanced PD groups** as it related to self-report ratings of **depression** or **anxiety**. (See Table 4)
- There was a significant difference between the **Early PD group** and **Advanced 11+ years PD group** for “**state anxiety**,” with otherwise an absence of statistically significant differences of anxiety ratings between groups as it relates to disease duration. (See Table 5)

Figure 3. Health-Related Quality of Life (PDQ-8) and Disease Duration



Higher scores reflect worse health-related quality of life

* Significant difference between the Early PD group and Advanced PD group, with the Advanced PD group having worse ratings of health-related quality of life.

Table 2. Disease duration and General Quality of Life

How would you rate your quality of life?	Early PD (<6 years) N=250	Advanced PD (6-10 years) N=222	Advanced PD (11+ years) N=338
Could not be worse	1%	0%	1%
Bad	2%	4%	4%
Fair *	17%	31%	33%
Good *	61%	54%	50%
Excellent *	20%	11%	12%

* Statistically significant difference between **Early PD** and both **Advanced PD 6-10 years** and **11+ years**, without significant differences between the **Advanced PD 6-10 year group** and **Advanced PD 11+ year group**.

Table 3. Disease duration and Report of Resilience

To what extent do you perceive yourself as a resilient individual	Early PD (<6 years) N=250	Advanced PD (6-10 years) N=222	Advanced PD (11+ years) N=338
Not at all	1%	2%	2%
Sometimes *	19%	25%	25%
Often*	48%	53%	54%
Always*	32%	20%	19%

* Statistically significant difference between **Early PD** and both **Advanced PD 6-10 years** and **11+ years**, without significant differences between the **Advanced PD 6-10 year group** and **Advanced PD 11+ year group**.

Table 4. Disease Duration and Self-report Depression and Anxiety

Severity of Symptoms	Early PD (<6 years) N=253	Advanced PD (6-10 years) N=222	Advanced PD (11+ years) N=338
Depression			
Not at all	32%	28%	26%
Mild	48%	51%	48%
Moderate	19%	19%	25%
Severe	1%	2%	1%
Anxiety			
Not at all	22%	20%	20%
Mild	44%	51%	47%
Moderate	29%	25%	29%
Severe	4%	4%	4%

Table 5. Disease Duration and Average Ratings of Anxiety (State Trait Anxiety Inventory)

Anxiety	Early PD group (N=254)	Advanced PD group (6-10 years) (N=223)	Advanced PD group (11+ years) (N=342)
State Anxiety (current)	34.73*	36.53	37.32*
Trait Anxiety (in general)	34.40	36.29	35.81

* Statistically significant difference for state anxiety between **Early PD State Anxiety** and **Advanced PD 11+ years**

DBS Specific Questions (N=282):

- **Quality of Life ratings for DBS participants:**
 - 59% of the participants rated their quality of life as good to excellent
 - 35% reporting “fair” quality of life
 - 5% reporting “bad” quality of life
 - <1% reporting that quality of life “could not be worse”
- **To what extent has DBS improved quality of life:**
 - 42% reported that DBS “extremely” improved quality of life
 - 35% reported that DBS “moderately” improved quality of life
 - 18% reported that DBS “mildly” improved quality of life
 - 5% reported that DBS did not improve quality of life
- **To what extent has DBS improved self-confidence?**
 - 23% reported that DBS “extremely” improved self-confidence
 - 42% reported that DBS “moderately” improved self-confidence
 - 25% reported that DBS “mildly” improved self-confidence
 - 10% reported that DBS did not improve self-confidence
- **To what extent has DBS helped create a positive outlook on your future?**
 - 27% reported that DBS was “extremely” helpful in creating a positive outlook on the future
 - 38% reported that DBS was “moderately” helpful in creating a positive outlook on the future
 - 24% reported that DBS was “mildly” helpful in creating a positive outlook on the future
 - 11% reported that DBS did not help to create a positive outlook on the future
- **To what extent has DBS increased your engagement in activities within your household?**
 - 32% reported that DBS was “extremely” helpful in increasing engagement in activities within the home
 - 43% reported that DBS was “moderately” helpful in increasing engagement in activities within the home
 - 17% reported that DBS was “mildly” helpful in increasing engagement in activities within the home
 - 8% reported that DBS did not help increase engagement in activities within the home
- **To what extent has DBS increased your engagement in activities outside of the home?**
 - 26% reported that DBS was “extremely” helpful in increasing engagement in activities outside of the home
 - 42% reported that DBS was “moderately” helpful in increasing engagement in activities outside of the home
 - 21% reported that DBS was “mildly” helpful in increasing engagement in activities outside of the home
 - 11% reported that DBS did not help increase engagement in activities outside of the home
- **To what extent has DBS increased your engagement in social activities (e.g., spending time with others)?**
 - 19% reported that DBS was “extremely” helpful in increasing engagement in social activities
 - 37% reported that DBS was “moderately” helpful in increasing engagement in social activities
 - 28% reported that DBS was “mildly” helpful in increasing engagement in social activities
 - 16% reported that DBS did not help to increase engagement in social activities
- **How satisfied are you with the effectiveness for DBS?**
 - 37% reported that they are “completely satisfied” with the effectiveness of DBS
 - 46% reported that they are “somewhat satisfied” with the effectiveness of DBS
 - 5% reported that they are “indifferent” with the effectiveness of DBS
 - 10% reported that they are “somewhat dissatisfied” with the effectiveness of DBS
 - 2% reported that they are “completely dissatisfied” with the effectiveness of DBS

SUMMARY AND CONCLUSIONS

Individuals with Parkinson's disease (PD) experience a number of motor and non-motor symptoms that can cause distress and reduce quality of life. Although there has been research on coping with PD^{5,6,7}, there has been little research emphasizing the patient's perspective about resilience in the context of PD. The results of this study are discussed below in the context of the objectives of this report.

1. To obtain the “patients’ perspective” about their sense of resilience, and to better understand how resilience relates to other factors, such as attitude, self-confidence, emotional well-being, health-related quality of life, and quality of life in general.
 - 75% of the participants perceive themselves as either “often” or “always” resilient, with 23% perceiving themselves as “sometimes” resilient, and 2% reporting that they do not feel resilient at all.
 - 95% of the participants report at least “fair” quality of life (69% reported “good” to “excellent” quality of life).
 - The average rating of optimism revealed that participants are generally “slightly optimistic,” and experience moderate levels of self-confidence when faced with challenges or problems.
 - Feelings of depression and anxiety are highly prevalent in individuals with PD, with more than 20% endorsing at least moderate levels of depression and more than 30% endorsing at least moderate levels of anxiety.
 - Higher ratings of resilience and self-confidence were significantly related to better quality of life, more optimism, less pessimism, less health-related difficulties, less depression, and less anxiety.
 - Higher ratings of health-related quality of life (PDQ-8) were significantly related to higher optimism, resilience, and self-confidence and less difficulties with depression, stigma and social support.
 - Thus, it is important to monitor psychological status and to consider rendering intervention if individuals experience a poor sense of resilience, low self-confidence, emotional distress and pessimism, as these factors are directly related to quality of life and health-related quality of life.
 - For individuals experiencing significantly elevated levels of depression and/or anxiety, it is important to seek treatment for such symptoms, as emotional disturbance can prevent adaptive coping and adversely impact quality of life.
 - Notably, although there is a relationship between attitude, resilience, emotional well-being, and self-confidence, health-related quality of life and general perception of quality of life, these findings do not imply causality. Other research, however, has found that higher levels of resilience has been associated with less depression¹⁸, and a lack of resilience has been associated with depression, apathy, and disability¹⁹.
2. To compare and contrast resilience and the factors related to resilience for **DBS** and **Non-DBS** patients in both a **Younger PD group** and **Older PD group**.
 - There were no differences between the **DBS** and **Non-DBS groups** within the **Younger** and **Older PD groups** as it relates to the level of optimism, self-confidence, resilience, quality of life, depression, or anxiety.
 - Age was not related to general attitude, self-confidence, resilience, quality of life, or emotional disturbance.
3. To investigate the relationship between **disease duration**, resilience, and factors related to resilience for **DBS** and **Non-DBS** patients.
 - The progression of PD takes its toll not only on perceived physical and functional challenges commonly faced by individuals with PD (e.g., as cited in the literature and as indicated on the PDQ-8 within this study), but also on psychological constructs, such as optimism, self-confidence, and quality of life in general.

- Self-reported resilience was significantly different between the **Early PD group (PD<6 years)** and the **Advanced PD group (PD 6+ years)**, with the **Earlier PD group** endorsing greater levels of resilience than the **Advanced PD group**.
 - The greatest change to resilience and self-confidence/self-efficacy occurred around 6 to 10 years post disease onset, which is possibly influenced by marked symptom changes in disease progression (e.g., the emergence of motor complications and fluctuations). As the disease progresses for individuals within the advanced stages of PD (comparing **Advanced PD 6-10 years** to **Advanced PD 11+ years**), however, there was not a significant difference in reported resilience and self-confidence (or attitude).
 - Increasing vigilance towards and intervention (e.g., cognitive-behavioral therapy) for the possible shifts in psychological well-being during this apparent vulnerable time frame (**PD 6-10 years**) may assist in improving one's sense of resilience and adjustment related difficulties.
- As for emotional well-being, there were no differences between the **Early PD group** and the **Advanced PD group** as it related to ratings of depression and "trait anxiety" (general feelings of anxiety). The **Advanced PD 11+ years group** had a higher rating of "state anxiety" (anxiety that exists "right now") when compared to the **Early PD group**. It is unclear as to why "state anxiety" was higher for the **Advanced PD 11+ years group** at the time of participation.

DBS Therapy:

- DBS therapy has had a favorable impact on quality of life, self-confidence, and outlook on the future.
 - 95% of the individuals who have had DBS therapy indicated that DBS therapy has improved their quality of life.
 - 90% of the participants who have had DBS therapy believe that DBS therapy has improved their self-confidence.
 - 89% of the participants who have had DBS therapy believe that DBS therapy has improved their outlook on the future.
- 83% of the participants who had DBS therapy experienced satisfaction with this intervention, with 12% reporting that they were dissatisfied with DBS therapy (5% were not satisfied nor dissatisfied).
- A significant portion of participants who have had DBS therapy reported that DBS therapy significantly improved their ability to engage in activities in social settings inside and outside of the home.
- Thus, if a good candidate for DBS therapy, such intervention may lead to improved self-confidence, general outlook, engagement in activities, and quality of life.

Recommendations For Maintaining Resilience:

Maintaining a sense of resilience and applying effective coping strategies (for people with PD and their carers) may be difficult as complications and functional decline emerge within the course of PD. The following comments and concepts have been discussed in the resilience and coping literature and may be helpful with coping with PD.

The following coping strategies have been found to be effective coping techniques and have been found to relate to higher reports of health-related quality of life:

- Frazier and Marsh⁶ encourage individuals to **regard PD obstacles as challenges to be overcome**, rather than hopeless barriers. They indicated that a **positive approach** allows for a sense of pride, control, and hopefulness that can lead to more effective coping.
- More active strategies, such as using **task-oriented strategies** (being proactive about coping with their illness, such as learning about symptom management, exercise, etc.), using **distraction techniques** (uses actions and thoughts that are aimed at avoiding preoccupation with the health problem), and maintaining a **positive attitude** lead to higher ratings of quality of life⁷.

- **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), and **Distancing** (e.g., I turn to other activities to take my mind off things) have been found to help in coping with adversity^{5,20}.
- Maintaining a positive attitude, optimism, and happiness, and investing energy in controlling the variables over which we have control, and not focusing on or magnifying symptoms challenges that are out of our control can lead to longer lives, less disability, and increased quality of life²¹.
- The American Psychological Association suggests “10 Ways to Build Resilience,” which include: (1) maintain good relationships with close family members, friends and others; (2) avoid seeing crises or stressful events as unbearable problems; (3) accept circumstances that cannot be changed; (4) develop realistic goals and move towards them; (5) take decisive actions in adverse situations; (6) look for opportunities of self-discovery after a struggle with loss; (7) develop self-confidence; (8) keep a long-term perspective and consider the stressful event in a broader context; (9) maintain a hopeful outlook, expecting good things and visualizing what is wished; (10) take care of one’s mind and body, exercising regularly, paying attention to one’s own needs and feelings²².
- Engage in treatment with a mental health professional: participating in cognitive-behavioral therapy, motivational interviewing, or supportive problem-solving techniques may assist in developing or maintaining a sense of resilience and improving coping strategies.

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REFERENCES

1. Freedman, R. Editorial (2008). Coping, resilience, and outcome. *Am Journal of Psych*, 165: 1505-1506.
2. Philippe, F., Lecours, S., Beaulieu-Pelletier, G. (2008). Resilience and positive emotions: Examining the role of emotional memories. *J Pers.* 77:139-175.
3. Rasmussen, H, Scheier, M.F., Greenhouse, J.B. (2009). Optimism and physical health: A meta-analytic review. *Ann Behav Med.* 37:239-256.
4. Tusaie, K, & Dyer, J. (2004). Resilience: a historical review of the construct. *Holist Nurs Pract*, 18:3-8.
5. Frazier, L.D. (2002). Stability and change in patterns of coping with Parkinson's disease. *Int. J. Aging Hum Dev.*, 55(3): 207-31.
6. Frazier, L. & Marsh, L. (2006). Coping. In *Psychiatric Issues in Parkinson's Disease: A Practical Guide* (eds. Menza and Marsh). Taylor & Francis: United Kingdom.
7. Wertheimer, J., Smith, J., Trepatschko, V., Kramer, R., Wherry, J., Walton, C., & Tuchman, M. (2008). Differential impact of coping styles on quality of life for individuals with Parkinson's disease with and without deep brain stimulation. The Parkinson Alliance website – "DBS4PD.org" http://www.dbs4pd.org/UserFiles/File/Coping_report07.pdf
8. Robottom, B.J., Gruber-Baldini, A.L., Anderson, K.E., Reich, S.G., Fishman, P.S., Weiner, W.J., Shulman, L.M. (2012). What determines resilience in patients with Parkinson's disease? *Parkinsonism Relat Disord* 18(2):174-7.
9. Scheier, M. & Carver, C. (1985). Optimism, coping, and health: Assessment and implications of generalized outcome expectancies. *Health Psychology*, 4: 219-247.
10. Schwarzer, R. & Jerusalem, M. (1995) .Generalized Self-Efficacy Scale. In: Weinman, J, S Wright, and M Johnson (eds.) *Measures in health psychology: A user's portfolio, Causal and control beliefs.* pp. 35-37, Windsor England: NFER-NELSON.
11. Spielberger, C. D., Gorsuch, R. L., Lushene, R., Vagg, P. R., & Jacobs, G. A. (1983). *Manual for the State-Trait Anxiety Inventory*. Palo Alto, CA: Consulting Psychologists Press.
12. Jenkinson C, Fitzpatrick R, Peto V, Harris R, Saunders P. (2008) The Parkinson's Disease Questionnaire: PDQ-39 User Manual (including PDQ-8 and the PDQ Summary Index), Second Edition. Oxford: Health Services Research Unit. Marinus J, Visser M, Jenkinson C, A Stiggelbout. (2008) Evaluation of the Dutch version of the Parkinson's Disease Questionnaire 39. *Parkinsonism and Related Disorders*, 14, 24-27.
13. Peto, V., Jenkinson, C., Fitzpatrick, R., Greenhall, R. (1995). The development and validation of a short measure of functioning and well-being in patients with Parkinson's disease. *Quality of Life Research*, 4: 241-8.
14. Politis, M., Wu, K., Molloy, S., et al., (2010). Parkinson's Disease Symptoms: The Patient's Perspective. *Movement Disorders*, 25(11): 1646-1651.
15. Schrag, A. & Quinn, N. (2000). Dyskinesias and motor fluctuations in Parkinson's disease. A community-based study. *Brain*, 123: 2297-2305.
16. Bronstein, J., Tagliati, M., Alterman, R., et al. (2011). Deep Brain Stimulation for Parkinson Disease: An Expert Consensus and Review of Key Issues. *Archives of Neurology*, 68 (2): 165.
17. Deuschl, G., Schupbach, M., Knudsen, K., Pinski, M.O., Cornu, P., Rau, J., Agid, Y., Schade-Brittinger, C. (2013). Stimulation of the subthalamic nucleus at an earlier disease stage of Parkinson's disease: concept and standards of the EARLYSTIM-study. *Parkinsonism Relat Disord.* 19(1):56-61.
18. Hardy, S.E., Concato, J., & Gill, T.M. (2004). Resilience of community dwelling older persons. *J Am Geriatr Soc*, 52: 257-62.
19. Mehta, M., Whyte, E., Lenze, E., Hardy, S., Roumani, Y., Subashan, P., et al., (2008). *Int J Geriatr Psychiatry*, 23: 238-43.
20. Frazier, L., Cotrell, V., & Hooker, K. (2003). Possible selves and illness: a comparison of individuals with Parkinson's disease, early stage Alzheimer's disease, and healthy older adults. *Int. J. Behav. Dev.*, 27 (1): 1-11.
21. Seligman, M. (2002). *Authentic Happiness*. Free Press: A Division of Simon and Schuster, Inc.: New York, New York.
22. The American Psychological Association. "10 Ways to Build Resilience." [Online] Psychological Resilience, Wikipedia. http://en.wikipedia.org/wiki/Emotional_resilience.