

# PARKINSONALLIANCE

## **A brief description of the research projects conducted by The Parkinson Alliance (The full reports can be found on [parkinsonalliance.org](http://parkinsonalliance.org))**

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### **Sleep and Fatigue in Parkinson's Disease**

Sleep disturbances and fatigue are major problems in patients with Parkinson's disease (PD). We surveyed 433 people with Parkinson's disease to look at sleep habits, sleep quality and fatigue. We found that a majority of people reported moderate sleep problems. Factors such as mild depression and anxiety were associated with poor sleep. When looking at fatigue, those classified as good sleepers reported the least amount of fatigue.

Of the healthy habits surveyed, those that reported exercising daily had the lowest reported fatigue. The report further describes these results.

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### **Memory and Emotional Health in Parkinson's Disease**

Memory and emotional health are key elements to well-being and quality of life. While memory functions and emotional health are independent concepts in our day-to-day experiences, they are strongly related and can have a significant impact on our worldview and our function at home, in the community, and in the workplace. We had 444 participants in the survey. Approximately 70% of the participants reported having memory difficulties that interfere with day-to-day activities. Depression and anxiety were also prevalent for the participants, and individuals with anxiety and depression reported memory problems in far greater frequency than those individuals who did not experience emotional disturbance. The relationship between memory, emotional disturbance, and quality of life are discussed, and effective memory strategies and coping behaviors are also outlined in this report

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### **Managing Day-to-Day Stress and Resilience in Parkinson's Disease**

Acute and chronic stress are widespread throughout our global community today. The prolonged pandemic-related stressors seem to pile onto other life stressors so commonly experienced. For those with Parkinson's Disease (PD), not only are there increased feelings of isolation, anxiety, economic stressors, and sadness, grief or loss, motor symptoms and psychological stressors directly related to symptoms of PD can be exacerbated. When considering the vulnerability to psychological distress, understanding factors of resilience and specific coping strategies that can influence physical and mental quality of life are of great importance.

We had 567 participants in the survey. The top three stressors for the participants in this survey included having Parkinson's disease, experiencing functional difficulties, and being impacted by COVID-19, followed by stressors related to relationships. The majority of the participants perceive their level of stress as moderate in severity, and 70% indicated that they perceive themselves as resilient. The most frequently reported coping techniques included: connecting with family and friends, distraction techniques, physical exercise, managing attitude, and connecting with nature. The relationship between stress, physical and emotional health, and quality of life are also discussed. Effective coping behaviors are also outlined in this report.

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## **Motor Symptoms and Perceived Well-Being in Parkinson’s Disease**

Although motor symptoms are the defining diagnostic features of PD, the impact of non-motor symptoms on day-to-day life and QOL have been in the spotlight over the past several years. It is important, however, to revisit and draw attention to the current perspectives on motor symptoms and how the motor symptoms impact factors related to quality of life from the patient’s perspective. We had 922 participants in the survey. Balance problems were reported in the greatest frequency, followed by slowness of movement, medication-induced dyskinesias, stiffness, and then tremor. This survey found that balance problems and walking disturbance had the strongest relationship to lower ratings of quality of life when compared to other motor symptoms. Motor symptoms had a significant adverse impact on engagement in functional independence in the home, in day-to-day activities in general, and in social and community activities. The relationship between motor symptoms, emotional health, and quality of life are discussed in the survey report.

With increased attention to and awareness about the patient’s perspective about the experience of motor symptoms on daily life, there is an opportunity for improved intervention for individuals with PD, from symptom management to treatments that may help with adapting to and coping with such symptoms.

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## **Urinary Symptoms and Parkinson’s Disease**

Urination changes are common for many individuals with PD, yet, the understanding about urinary changes from the patient’s perspective remains understudied. Examples of urinary symptoms include increased frequency and urgency, having to urinate at night (disrupting sleep), incomplete emptying of the bladder, poor stream and straining. Urinary symptoms have recently been identified as an important influence on the quality of life of PD patients.

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## **Dyskinesia and Off-States in Parkinson’s Disease**

Dyskinesia (uncontrolled involuntary movements that can look like fidgeting or swaying) and wearing OFF-states are unfortunately a common experience for individuals with PD. Research has indicated that in patients treated with levodopa, dyskinesia can occur in approximately 50% of patients by 5 years and nearly 90% of patients by approximately 10 years of treatment. Dyskinesia and OFF-states are associated with impaired activities of daily living, decreased health-related quality of life, increased risk of falls, increased health care utilization, and increased strain on care providers. Although there are some improvements in the management of such symptoms, *continued research focused on understanding the experience of dyskinesia and OFF-states through the eyes and voice of the person with PD is very important.*

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## **Non-Motor Symptoms in Parkinson’s Disease**

Although the last several surveys conducted by The Parkinson Alliance emphasized a specific symptom related to PD, we wanted to dedicate a survey to a broad range of “non-motor symptoms.” Non-motor symptoms of PD may include: sleep disturbance, fatigue, cognitive difficulties (or thinking difficulties), depression, anxiety, hallucinations, sensory changes (i.e., changes in taste and smell; pain), low blood pressure resulting in dizziness and fainting spells, bowel and bladder difficulties, changes in vision, and swallowing difficulties, among others.

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## **Anxiety and Parkinson's Disease**

People with Parkinson's disease (PWP) commonly experience stress and anxiety. We continue to learn about the various manifestations, causes, treatments and implications of anxiety for PWP. What appears to be missing is a deeper appreciation of and awareness about the patient's perspective of his or her symptoms of anxiety and the perceived impact that anxiety has on day-to-day life. In our survey, 26% of the participants reported that anxiety was present prior to the diagnosis of PD, and 35% of the participants reported experiencing moderate to extreme generalized anxiety. A large number of the participants reported that anxiety has a moderate to extreme impact on everyday activities, including standing up and walking (fear of falling), interactions with others, engagement in hobbies/leisure activities, engagement in volunteer activities or work, health status, and overall "quality of life." Use of medications and engagement in non-medication-based intervention for anxiety were reported by many of the participants. Information about and recommendations pertaining to anxiety for individuals with PD are discussed in the report.

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## **Vision and Parkinson's Disease**

Eye movements and visual processing changes occur for individuals with PD, sometimes in subtle ways and sometimes in debilitating ways. Changes in vision may take the form of blurred vision, double vision, vision fatigue, depth perception and visual scanning difficulties, changes in color vision, hallucinations, eyelid drooping or involuntary closing, among other symptoms. There is very little research to date looking at how changes in vision impact the well-being of individuals with PD. The objective of the present study is to deepen our understanding about changes in vision and its impact on day-to-day activities and quality of life from the patient's perspective.

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## **Swallowing and Parkinson's Disease: Another Dimension of Well-being**

Swallowing and eating difficulties are common for individuals with PD, particularly as PD progresses. Swallowing and eating difficulties can impact feelings of safety, social relationships, and quality of life. Understanding the experience pertaining to swallowing difficulties and effective assessments and treatments from the patient's perspective is of great importance. Thus, the objective of the present study is to deepen our understanding about swallowing difficulties from the perspective of people living with Parkinson's Disease.

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## **Social Support and Parkinson's Disease: Another Dimension of Well-being**

Social support for PWP is complex and can be adversely impacted by symptoms of PD, including motor symptoms and non-motor symptoms such as changes in speech, cognition, psychiatric factors, and fatigue. Quality of and satisfaction with social support can have a significant impact on psychological well-being and quality of life. Furthermore, caregiver and patient quality of life are closely linked. Understanding concepts related to social support and the quality of relationships for PWP is of great importance. The objective of the present study is to deepen our understanding about social support from the perspective of PWP, particularly as it relates to gender, age and disease duration.

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## **Cognition and Parkinson's Disease**

Changes in thinking skills are common in People with Parkinson's, particularly involving slowness of thinking, memory, "word-finding difficulties", and managing more complex information. Significant cognitive difficulties can affect day-to-day functions, engagement in hobbies, treatment outcomes, and quality of life for

individuals with PD. Although our understanding about changes in thinking skills for those with PD continues to increase, there is limited understanding about how individuals in PD perceive cognitive difficulties and the related impact on “everyday activities.” The objective of the present study is to deepen our understanding about the perspective of individuals with PD pertaining to cognition and its relationship to day-to-day activities.

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### **Nutrition and Parkinson’s Disease**

For some, nutrition is conscientiously addressed each day; for others, nutrition is an afterthought, if a thought at all; for all, however, nutrition is a vital part of life. Nutrition gets quite a bit of attention in the general community, and it is getting more and more attention in the PD community. Understanding the complexity of this topic is daunting for many; add PD to the picture, and the challenges are magnified. How do individuals with PD manage nutrition in the context of general well-being, symptoms of PD, disease course, medications, etc.? How does nutrition management help with PD? The objective of the present study is to deepen our understanding about the perspective and habits of individuals with PD pertaining to nutrition and related variables.

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### **Patience and Well-being in Parkinson’s Disease**

As is known to many, both motor and non-motor symptoms can adversely impact many, if not all, facets of daily experiences for individuals with PD. Given increased challenges and reliance on others, I commonly think about the role of patience in my daily experience - patience with myself and patience with others, and even how my symptoms impact other persons' level of patience. Does having “patience” help improve the experience at hand?

In the most basic sense, patience is the propensity of a person to wait calmly in the face of frustration, adversity, or suffering. For the general public, patience has been found to allow the person to cope more adaptively with frustrations, and facilitates positive interpersonal interactions. Evidence has shown that patience is positively related to subjective well-being, positive coping, and virtues. The topic of patience as it relates to one’s well-being in the face of PD, however, has not been explored. The purpose of this study is to better understand patience in the lives of individuals with PD, particularly pertaining to the relationship between patience and well-being.

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### **Exercise and Parkinson’s Disease**

The concept of exercise being an important part of healthy living is not a new concept in our community. Additionally, there is research supporting the importance of exercise for individuals with PD, from symptom management (e.g., improving gait, balance, and freezing spells) to investigations about exercise and neuroprotection. What is less known is the “patient’s perspective” about exercise, including factors related to attitude and knowledge about exercise and PD, types of exercises in which individuals with PD engage, perceived benefit of exercise, and perceived barriers to exercise. The objective of the present study is to deepen our understanding about the perspective of individuals with PD pertaining to exercise and related variables.

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### **Autonomic Symptoms in Parkinson’s Disease**

The autonomic nervous system is a control system for the body that involves a number of functions such as cardiovascular functions, blood pressure, digestion, urination, sexual arousal, and swallowing. Autonomic

symptoms can have a significant impact on general functioning and health-related quality of life for individuals with PD. The objective of the present study is to increase the knowledge about autonomic symptoms in PD and its relationship to emotional well-being and quality of life.

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### **Sleep in Parkinson's Disease: A comparison between those with and without Deep Brain Stimulation**

Sleep disturbances are highly prevalent, are commonly incapacitating symptoms of PD, and are increasingly recognized as important contributors to reduced quality of life. A variety of sleep disorders may occur in PD, including excessive daytime sleepiness, insomnia (difficulty falling and/or staying asleep), nocturnal motor symptoms and sleep-related breathing disorders, and are often under-assessed and difficult to diagnose and treat. Improving our understating about sleep disturbance in PD for individuals with and without Deep Brain Stimulation may improve treatment intervention and increase the general sense of well-being for individuals with PD.

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### **Falls in Parkinson's Disease: Increasing our Understanding about Falls and Related Risk Factors**

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.

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### **Resilience in Parkinson's Disease: Practical Implications for Health Related Quality of Life**

Motor symptoms of PD and non-motor symptoms, such as disturbances in speech, sleep, thinking skills, energy levels, and emotional well-being, to name a few, can be debilitating and adversely impact quality of life. Resilience, the ability to adapt well to the difficulties in our lives including all kinds of adversity and stress, is thought to play a pivotal role in quality of life. Little is known, however, about resilience in individuals with PD, particularly as to how resilience impacts health-related quality of life. Improving our understating about resilience in PD may in turn improve the general sense of well-being for individuals with PD.

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### **Speech and Parkinson's Disease: Understanding the Experience of Individuals with and without Deep Brain Stimulation**

It is well known that many individuals with PD experience speech difficulties. Further research is necessary, however, to understand general aspects of speech and communication in individuals with PD, the patients' perspective of their speech disturbance and how speech difficulties present. Research has also found that deep brain stimulation (DBS) may impact speech. Thus, improving our understanding about the PD patients' experience with speech for those with and without DBS may help improve assessment of and treatment for speech difficulties, which can improve the quality of life for individuals with PD.

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## **A further look at Non-Motor Symptoms in Parkinson's disease for those with and without Deep Brain Stimulation (DBS)**

Historically, motor symptoms of PD were the most recognized features of this disease, but in more recent years, the debilitating aspects of non-motor symptoms, such as disturbances in speech, sleep, thinking skills, energy levels, and emotional well-being, to name a few, have gained more attention. Improving our understanding about how individuals with PD experience these symptoms may help improve assessment of and treatment for such symptoms, ultimately improving the quality of life of the individual with PD.

### **Health-Related Quality of Life and Attitude in Patients with Parkinson's Disease: Comparing those with and without Deep Brain Stimulation (Winter 2011)**

#### Bottom Line:

#### Attitude:

1. 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 when facing their daily challenges with PD. A minority of individuals also endorsed having a negative attitude as it relates to PD and how the condition may impact their future.
  - 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.

#### Health-Related Quality of Life:

2. Health-related quality of life was comparable between the **DBS group** and **Non-DBS group** with exception to Mobility (ability to get around) and Communication; the **DBS group** had greater difficulties with these functions.
  - 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.
3. 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 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).

#### Health-Related Quality of Life and Attitude Over a Four-Year Period:

4. 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.

5. 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.
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### **Fatigue and Apathy in Individuals with Parkinson’s Disease with and without Deep Brain Stimulation (Spring 2011)**

#### Bottom Line:

- 1) Almost half of the PWP experience both fatigue and apathy, with the majority of the participants experiencing fatigue and almost half of the participants experiencing apathy.
  - 2) Although there was not a difference for the experience of fatigue between the **DBS** and **Non-DBS groups**, there was a statistically significant difference in the experience of apathy between the groups. More individuals in the **DBS group** experienced apathy when compared to the **Non-DBS group**, and the **DBS group** also reported a longer duration of symptoms of apathy when compared to the **Non-DBS group**.
  - 3) Duration of PD does appear to differentially impact the experience of fatigue and apathy in individuals with PD. Specifically, a greater number of individuals who have had PD for at least 6 years (Advanced PD) endorsed clinically significant levels of fatigue and apathy when compared to those individuals who have had PD for less than 6 years (Early PD).  
Thus, the longer individuals endure the course of PD, the increased likelihood that symptoms of fatigue and apathy may manifest in day-to-day activities.
  - 4) Age (“**Younger PD group**” and “**Older PD group**”, 50 to 69 years and 70 years and older, respectively) was not a factor in the experience of apathy for the **DBS group**. In contrast, the **Older Non-DBS group** endorsed greater levels of apathy than the **Younger-Non-DBS group**.
  - 5) Symptoms of depression and anxiety were found to have a significant relationship with fatigue and apathy, indicating that the more depression or anxiety that a person experiences the greater the level of fatigue and apathy, with the converse also being true.
  - 6) Although there were elevated levels of depression, anxiety, and sleep disturbance for both groups, fatigue and apathy were found to be independent symptoms for individuals with PD. In other words, fatigue and apathy were found to be distinct symptoms commonly experienced in PD, as they appear to be experienced by individuals independent of psychological variables and sleep disturbance.
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### **Understanding Pain and Parkinson’s Disease for Individuals with and without Deep Brain Stimulation (Winter 2010)**

#### Bottom Line:

- 1) Pain in Parkinson’s disease (PD) is complex. It is clear that pain in people with Parkinson’s (PWP) is prevalent, under-assessed, and undertreated, and pain has a pervasive psychosocial impact on patients and their families.
- 2) Pain was prevalent in PD for both the **DBS** and **Non-DBS groups**, and was comparable in its overall “presentation.” Almost 65% of both groups experienced at least “discomfort” from their pain. For both the **DBS** and **Non-DBS groups**, pain was most commonly characterized as cramping, aching, and tiring/exhausting.
- 3) The most commonly endorsed locations of the pain in the body included the lower back (53%), the neck (41%), and the legs (31%).

- 4) Both the **DBS** and the **Non-DBS groups** perceived that pain interfered with many aspects of life, including general activity, mood, walking, work/housework, relationships, sleep, and enjoyment in life, with the most frequent ratings ranging between mild to moderate levels of interference.
  - 5) As persistent pain will affect the quality of life of the PWP as well as his/her family, looking at the effectiveness of treatments is equally as important as finding the cause of the symptoms. There are various types of treatments for pain including pain medications, adjustment of PD related medications (e.g. Sinemet), massage therapy, physical therapy, exercise, stretching, acupuncture, psychotherapy, and nutrition. Based on the current findings, integrating a treatment regimen for pain in the PWP is clearly indicated, and many individuals reported relief from an appropriate medication regimen to treat pain and an exercise program.
  - 6) There are currently mixed results in the literature regarding the impact of DBS on pain. Further research continues to be indicated.
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### **A closer look at Balance in Parkinson's disease for those with and without Deep Brain Stimulation: The patient's perspective (Winter 2009)**

#### Bottom Line:

- 1) The majority of individuals that underwent DBS believe that they have noticed improvement with balance, walking straight ahead, and ability to turn directions. When looking at specific age groups, however, (<50, 50-69, and 70+), DBS was reported to be the most helpful for the middle age group (ages 50 to 69).
  - 2) Even though the **DBS group** reported improvement with balance-related functions, the **DBS group** reported more falls than the **Non-DBS group** (within a year's time period).
  - 3) The **DBS group** had a disease duration that was almost double that of the **Non-DBS group**. With that in mind, and knowing that balance and gait abnormalities are strongly related with progression of disease, it is important to note that the two groups were virtually indistinguishable in terms of balance and gait. Thus, DBS may indeed be having a positive effect.
  - 4) Approximately half of each group (**DBS** and **Non-DBS groups**) identified that they used assistive devices, and the majority of both groups found the devices helpful.
  - 5) When looking at the overall pattern of responses on the Activities-Specific Balance Confidence Scale (ABC Scale), The **DBS group** and **Non-DBS group** had similar balance confidence ratings.
  - 6) Balance confidence is clearly impacted by symptoms of depression for both the **DBS group** and **Non-DBS group**.
  - 7) Balance confidence is related to perceived cognitive capability in the **DBS group**, particularly as it relates to functions within the domain of executive control (e.g., focusing, transitioning, planning, organizing, multi-tasking, and problem solving). Difficulties with attention and focus, in particular, were determinants in the level of one's report of balance confidence. Thus, understanding the PD patient's cognitive capability and related perception of cognitive capability in the DBS population is critical for understanding reasons for a specific level of balance confidence.
  - 8) Sleep disturbance had a significant relationship to the participants' balance confidence. The less sleep on average that individuals get per night, the less balance confidence they had as well.
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### **Quality of Speech in Individuals with Parkinson's Disease with and without Deep Brain Stimulation (Spring 2008)**

#### Bottom Line:



- 1) The vast majority of the participants in both groups perceived changes in speech (**DBS=92%**; **Non-DBS=87%**), reflecting the importance of further research in this area and the need for improved intervention.
  - 2) Although both the **DBS** and **Non-DBS** groups reported significant difficulties with speech, the **DBS** group reported more severe speech disruption and related problems than the **Non-DBS** group.
  - 3) The result from the Voice Handicap Index (VHI) revealed that the **DBS** group had reported greater negative effects of voice disturbance on their daily life (from having physical difficulties to functional limitations of communication), and that they have a greater adverse emotional response to their voice difficulty when compared to the **Non-DBS** group.
  - 4) It is notable that almost 70% of participants that underwent **DBS** were not aware that one common adverse side effect from this treatment is slurred speech. It is also notable that 85% of those experiencing speech changes indicated that they would go through with the surgery again even knowing that slurred speech or other speech disturbance was likely.
  - 5) Treatment options for voice difficulties related to PD as well as to DBS need to be further evaluated. As seen in our data, not many of the participants had undergone Speech Therapy, and for those who engaged in treatments for their speech disturbance, the majority of each group reported having at least a modest success rate.
  - 6) It appears that there is limited accessibility and inconsistent/infrequent utilization of speech therapy. Better treatment accessibility and/or utilization needs to occur as such a great number of individuals with PWP are affected by speech difficulties.
  - 7) Speech difficulties can have a devastating impact on both general communication with others, and socialization and quality of life can be significantly reduced due to speech disturbance. Further investigation pertaining to the “patient’s perception” of their speech symptoms of PD as well as how it is affected by DBS is warranted.
  - 8) Future studies should investigate the frequency of recommendations for speech therapy, the accessibility of speech therapy, and the utilization of speech therapy in the PD population.
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### **Differential Impact of Coping Styles on Quality of Life for Individuals with Parkinson's Disease with and without DBS (Fall 2007)**

#### Bottom Line:

- 1) There was no difference between the **DBS group** and the **Non-DBS group** as it related to the type of coping strategies used: 1. Distraction (using actions and thoughts to avoid preoccupation with health problems), 2. Palliative (a more passive approach to coping, such as finding comfortable surroundings), 3. Instrumental (a pro-active, task-oriented approach), and 4. Emotional Preoccupation (focusing on emotional factors related to their health problems).
- 2) Individuals with Parkinson’s disease tended to use methods of coping 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 were related to focusing on emotional consequences related to their health problems. They tended not to use a passive, comfort-seeking approach to coping.
- 3) Coping strategies 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.
- 4) Our findings regarding the relationship between higher reports of quality of life and positive expectations need 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 also for the carers. 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 as it relates to potential challenges with this disease.

### **The Relationship between Sleep and Emotional Well-being in Individuals with Parkinson's disease with and without Deep Brain Stimulation (February 2007)**

#### Bottom Line:

- 1) In this study, we found that depression and anxiety are related to many aspects of sleeping difficulties as it specifically relates to sleep problems commonly experienced within the PD population.
  - 2) As expected, when looking at the differences between the groups, for both the **DBS group** and the **Non-DBS group**, sleep problems were related to anxiety and depression. It has been proven in research that sleep problems can cause emotional distress, and likewise, emotional distress can cause sleep disturbance.
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### **Sleep in Individuals with Parkinson's Disease with and without Deep Brain Stimulation (January 2007)**

#### Bottom Line:

- 1) General estimates suggest that approximately 20-47% of PWP will have sleep disturbances including insomnia, restless legs, vivid nightmares, and acting out dreams. Consistent with the literature, we found that the participants in this study (both **DBS and Non-DBS participants**) experience significant sleep disturbance as is commonly seen in the general PD population
  - 2) Even though sleep disturbance was found to be quite prominent for both the **DBS and Non-DBS** groups, we found that **DBS-STN** had a significant and positive impact on the quality of nighttime sleep. In other words, our research reflects that the **Non-DBS group reported greater incidence of sleep disturbance** across many symptoms of sleep dysfunction as compared to the **DBS group**. This can likely be attributed to the fact that this surgical procedure minimizes, if not eliminates, some of the motor symptoms that are known to cause fragmented or disrupted sleep.
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### **Anxiety and Depression in Individuals with Parkinson's Disease with and without Deep Brain Stimulation (December 2006)**

#### Bottom Line:

- 1) Both the **DBS group** and the **Non-DBS group** experienced significant levels of anxiety and depression.
- 2) A larger percentage of the **Non-DBS group** was found to be experiencing anxiety when compared to the **DBS group**.
- 3) The general prevalence of anxiety within adults nationwide (ages 18+) is 18.1%, which is equivalent to the findings for the **DBS group** in this study. A significantly higher number of the **Non-DBS group** (25%) was found to be experiencing anxiety.
- 4) Consistent with the literature, both groups reported a higher percentage of depression compared to the general adult population in the United States, which is about 9.5%. 24% of the **DBS group** and 29% of the **Non-DBS group** reported elevated scores on a measure of depression, reaffirming that depression is very prevalent in PD.
- 5) Approximately half of the **DBS group** indicated that they experienced changes in their level of anxiety and depression following DBS, the majority of whom stated that they experienced less emotional distress.

- 6) The findings of this study indicated the majority of participants with psychiatric symptoms tend to be managed by either the patient's neurologist (in the main) or primary care physician.

### **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) (April 2006)**

#### Bottom Line:

- 1) 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 experience of the PD symptoms that would otherwise be worse.
  - 2) Within the **DBS group**, 94% were satisfied with the overall effect of DBS. There were only a few treatment- or outcome-related variables that revealed dissatisfaction with DBS, and they included distance to travel to meet with a programmer, speech problems, and weight gain.
  - 3) The DBS group reported fewer problems with tremor and dyskinesias than the Non-DBS group. In our research, there were significantly more reports of balance problems for the DBS group than the non-DBS group.
  - 4) 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.
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### **Comparing Quality of Life in Parkinson's Disease Patient's with and without Deep Brain Stimulation (2005)**

#### Bottom Line:

- 1) Essentially equivalent levels of overall satisfaction with health, quality of life, and movement disorder symptoms were observed between the two groups with one exception: speech problems. The **DBS group** reported greater problems with articulation and fluency of speech.
  - 2) Our findings indicate, not unexpectedly, that as the duration of PD increases in the **non-DBS group**, severity of movement disorder increases. For the **DBS group**, the DBS appeared to disrupt the typical relationship between duration of PD and severity of movement disorder, as they reported less severity of problems related to the common movement difficulties related to PD. Although indirect and based solely on self-report data, these findings are consistent with the finding of other controlled studies that support the efficacy of DBS for the improvement of movement disorder symptoms.
  - 3) Depression, in particular, plays a major role in one's quality of life for both the **DBS group** and **Non-DBS group**, the more depressed one is, the worse their report of quality of life.
  - 4) Notably, there were *no significant differences between the two groups on a measure of depression*. Thus, DBS does not generally lead to depression or worsening of QoL.
  - 5) There were **no significant differences between the two groups on a measure of depression**, even after controlling for disease duration. In the DBS group, 39% reported mild levels of depression, 16% reported moderate levels of depression, and 4% reported severe levels of depression. In the Non-DBS group, 35% reported mild levels of depression, 21% reported moderate levels of depression, and 5% reported severe levels of depression.
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## **Quality of Life and Depression Following Deep Brain Stimulation of the Subthalamic Nucleus (DBS-STN) (November 2004)**

### Bottom Line:

- 1) A large percentage of participants are experiencing symptoms of depression, and Quality of Life, as expected, was strongly related to symptoms of depression.
  - 2) 53% of the participants in our study scored at least mild depression (35%=mild; 13% moderate; 5% severe).
  - 3) For individuals with PD who have undergone DBS, out of 108 participants, some of the most problematic symptoms in order of most to least reported are speech (34%), balance (33%), gait (26%), freezing (15%), rigidity (14%), tremor (12%), bradykinesia (11%), and dyskinesia (10%). As seen here, the top three symptoms that are reported to be the most troubling include speech, balance, and gait problems (speech being the most troubling symptom).
  - 4) As a whole, most participants who have undergone DBS reported high satisfaction with the treatment and outcome related to DBS therapy.
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## **Focus 1 Report (January 2004)**

### **Perception of Motor symptoms following DBS-STN:**

#### Bottom Line:

- 1) DBS-STN is an effective therapeutic intervention to treat motor symptoms associated with PD, as participants in this study report improvement in with a couple of the cardinal motor symptoms.
- 2) The majority of individuals who underwent DBS-STN reported an improvement in tremor, rigidity, freezing, and bradykinesia (slowness in movement). Quite a few individuals reported some gait improvement following the surgery, but there were several that did not experience any change in gait following the surgery.
- 3) The majority of patients in this study reported no change in balance problems following DBS-STN.