

## A summary of survey reports conducted by The Parkinson Alliance

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

*The data for this project are currently being collected.*

Our next research project is focusing on quality of life in individuals with Parkinson's disease (PD) for those **with** and **without Deep Brain Stimulation (DBS)**. Individuals with PD are confronted with motor and non-motor symptoms as well as challenges related to psychosocial issues (e.g., impact of PD on social relationships, recreational activities, employment, etc.), which have an impact on quality of life. Understanding "quality of life" and the variables that directly impact it are very important in helping to improve assessment of and treatment for individuals with PD. This study is designed to investigate variables related to quality of life in individuals with PD, with a particular interest in looking at the relationship between quality of life and "attitude."

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### **Fatigue and Apathy in Individuals with Parkinson's Disease who have and have not undergone Deep Brain Stimulation (Spring 2011)**

*The data have been collected, and are currently being analyzed.*

Fatigue and apathy are very common symptoms for individuals with PD. Studies suggest that over half of the individuals with PD may experience symptoms of fatigue and/or apathy. Additionally, there are many factors that may contribute to these symptoms, including sleep disturbance and depression. We are investigating how individuals with PD experience fatigue and apathy, and we will be looking at variables that relate to these symptoms. Furthermore, we will be investigating whether or not the experience of fatigue and apathy differs between individuals with PD who have and have not had DBS.

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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, having a pervasive psychosocial impact on patients and their families.
- 2) Pain was prevalent in PD for both the **DBS** and **Non-DBS group**, 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 group** and the **Non-DBS group** 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 common 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 condition. 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) The effect of DBS on pain in PD is not fully known as DBS is still relatively in its infancy and researchers and clinicians continually discover more and more about DBS the longer it is used with PWP. There are currently mixed results in the literature regarding the impact of DBS on pain. Further research is 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 participant's 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 speed 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.
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## **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**.

### Additional Details:

- 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.

- 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.
- 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.
- 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.

#### Additional Details:

- 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.
- 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.

### **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.

Additional Details:

- 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:

A large percentage of participants are experiencing symptoms of depression, and Quality of Life, as expected, was strongly related to symptoms of depression.

Additional Details:

- 53% of the participants in our study scored at least mild depression (35%=mild; 13% moderate; 5% severe).
  - 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).
  - 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:

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.

#### Additional Details:

- 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.
  - The majority of patients in this study reported no change in balance problems following DBS-STN.
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