

## Understanding Pain and Parkinson's Disease for Individuals with and without DBS

### Introduction

Parkinson's disease (PD) is classically defined as a movement disorder with primary symptoms of tremor, rigidity, bradykinesia, disturbance of gait, and postural control problems.<sup>1</sup> Pain, however, is increasingly recognized as a disabling symptom and is cited as a major complaint, often prior to confirmation of a PD diagnosis.<sup>2,3</sup> Little is known about the pain experienced by People with Parkinson's Disease (PWP), or how PWP find relief from painful symptoms. Furthermore, some studies have found that Deep Brain Stimulation (DBS) may alter the experience of pain in PD.<sup>4,5,6</sup> Other studies, however, did not find differences between those PD patients who have DBS and those who do not.<sup>7</sup>

The percentage of PD patients experiencing pain varies considerably, ranging from 30 to 85%.<sup>8,9,10,11,12</sup> This wide variation in pain estimates is related to inconsistent definitions of pain and lack of utilization of valid pain measures. Numerous published reviews provide insight into the difficulties of assessing and managing pain in PD, which contribute to a limited understanding of the complexity of the pain experiences and the impact of pain on physical and psychosocial well-being. In contrast to the estimates of PD patients who experience pain, studies assessing pain in older adults "in the general population" estimate that 25% - 50% of elders experience persistent pain.<sup>13</sup> There have been studies to support this difference.<sup>12,14,10</sup> When comparing the general aging population without PD to PWP, pain is endorsed more often in PWP. Despite this difference in the occurrence of pain, little work has been devoted to assist in understanding the mechanisms that contribute to the experience of pain in PWP.

Furthermore, painful symptoms in PD are inconsistently described, poorly understood, and under treated. Several researchers suggest PD pain may be related to motor and musculoskeletal complications from the disease itself.<sup>8,9,12</sup> Further complicating the discussion of pain in PD is the obvious contribution of pain from other medical conditions from which PD patients may be suffering and are unrelated to PD diagnosis, such as, bursitis, osteoarthritis, diabetes, degenerative disc disease, tendonitis, prior injuries, and disc herniation,<sup>9,10</sup> or from musculoskeletal and rheumatic pain that are commonly found in the general population.<sup>15</sup>

### Objective

As Ford<sup>12</sup> (2010) indicated, the "most important diagnostic tool is the patient's history" of pain. Understanding the perspective of the PWP as it relates to pain is imperative in the quest to better understand this disease and to provide optimal care for these individuals. The goal of this study was to examine the experiences that PWP may have with pain. In addition, we compared the experience of pain in individuals with PD who have undergone DBS (**DBS group**) to those who have not had DBS (**Non-DBS group**) to identify the impact of DBS on the PWP's experience of pain.

## Methods

The participants were recruited from a variety of sources. Some had participated in previous surveys conducted by The Parkinson Alliance; others responded to study announcements in medical clinics around the country, and still others found out about the study through their participation in local PD support groups, The Parkinson Alliance website ([www.parkinsonalliance.org](http://www.parkinsonalliance.org)), or our affiliate website devoted to DBS ([www.dbs-stn.org](http://www.dbs-stn.org)). Participants came from around the United States, Canada, and India. The participants in this report included 161 individuals with PD who underwent DBS (**DBS group**) and 193 individuals with PD without DBS (**Non-DBS group**). Please see Table 1 for the demographic information.

**Questionnaires:** The participants in this study completed a demographics questionnaire, the Brief Pain Inventory, and the McGill Pain Questionnaire (Short Form).

**The Demographic Questionnaire:** The demographic questionnaire included questions related to background information of the participants as well as questions related to one's opinion about their pain, current treatment providers, activities related to treatment for pain, and questions related to DBS for those who have undergone DBS therapy.

**The Brief Pain Inventory<sup>16</sup>:** The scale is composed of 15 items. Two subscales can be created, pain severity and pain interference. The subscale for pain severity consists of four items rated from 0 = "no pain" to 10 = "worst pain." For example, "Please rate your pain by circling the one number that best describes your pain on the AVERAGE" using the scale of "0" to "10." Pain severity was the average of these 4 scores. The pain severity subscale has a range of zero to 40 (Fortner et al., 2003). An overall "pain interference" score is calculated by creating a total score for the ratings related to pain interfering with general activity, mood, walking ability, normal work or housework, relations with others, sleep, and enjoyment in life. The interference subscale has a range from zero to 70.

**The Short Form McGill Pain Questionnaire (SF-MPQ)<sup>17</sup>:** The SF-MPQ consists of 15 adjectives to characterize symptoms of pain to which an individual may relate. The scale yielded two subscales, "sensory" and "affective" descriptors of pain. The "sensory" descriptors relate to more physical experiences, including throbbing, shooting, stabbing, sharp, cramping, gnawing, hot/burning, aching, heavy, tender, and splitting. In contrast, the "affective" descriptors relate to more emotional descriptors, including tiring-exhausting, sickening, fearful, and punishing-cruel. Each descriptor is scored on a four-point scale: 0 = none, 1 = mild, 2 = moderate, and 3 = severe.<sup>18</sup> This questionnaire also provided the opportunity to rate the overall severity of the individual's pain, from "no pain" to "excruciating pain."

## Results

**Table 1. Demographics and Clinical Features of the Sample**

Variable	DBS (n=161)	Non-DBS (n=193)
Mean Age in years	64	69
Duration of PD in years *	15	8
Percent Male	62%	58%
Percent Female	38%	42%
Percent Married	77%	74%
Percent Living with Someone	89%	83%
Mean Age of PD onset (in years)	49	60
Age at Time of DBS	59	n/a
Average Time since DBS-STN (in years)	5.4	n/a
DBS Target STN	86%	n/a
DBS Target GPi	7%	n/a
DBS Target Thalamus	1%	n/a
Bilateral Stimulation	90%	n/a
Unilateral Stimulation	10%	n/a

\*Denotes significant differences between the groups

### Age and Duration of PD within the Two Groups:

- The majority of the participants were between the ages 50-69 (See Figure 1).
- The **DBS group** had a longer duration than the **Non-DBS group** (See Figure 2).

The majority of the participants were within the range of 50-69 years of age for both groups, followed by a cohort that was older than 70 years of age. There were only a few participants that were younger than 50 years of age (see Figure 1). There was a significant difference for duration of PD between the two groups (see Figure 2). The **DBS group** had PD for a longer duration than the **Non-DBS group**. For research purposes, it is important to take duration of PD into consideration, which was done for all of the results reported below.

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

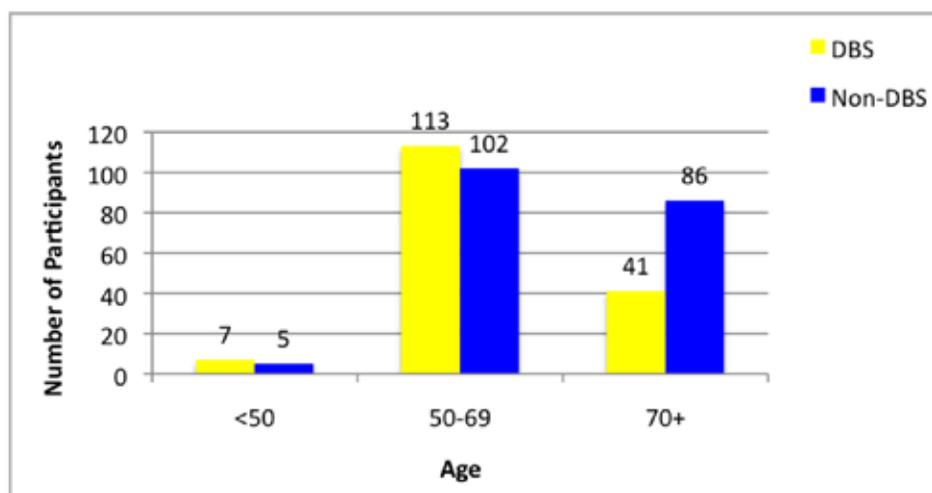
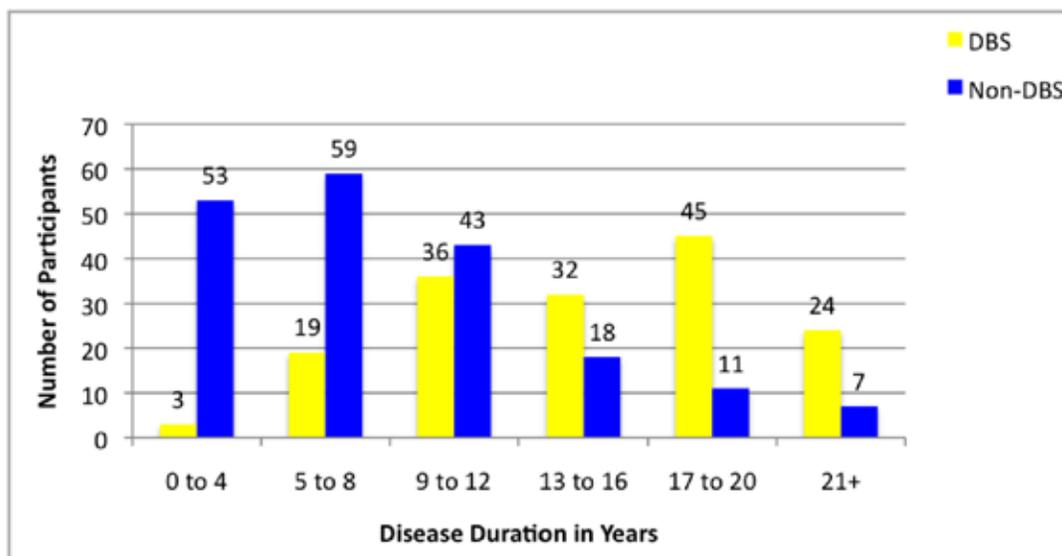


Figure 2. Disease Duration Categories (in Years) for DBS and Non-DBS groups



**Pain:**

- The majority of both groups endorsed significant elevations of pain (See Table 2).
- Most participants believed their pain was directly related to PD.

On the McGill Pain Questionnaire, 79% of the **DBS group** and 82% of the **Non-DBS group** reported experiencing some level of pain. When looking at the how the participants “characterized” their pain, 64% of both the **DBS group** and **Non-DBS group** rated the pain experience between “discomfort” and “excruciating” (see Table 2), indicating that the majority of participants experience pain that is, at the very least, disturbing to them. Of those who experienced pain, 79% of the **DBS group** and 73% of the **Non-DBS group** believed that their pain was directly related to PD symptoms.

Table 2. Pain Severity Rating: Short Form-McGill Pain Questionnaire:

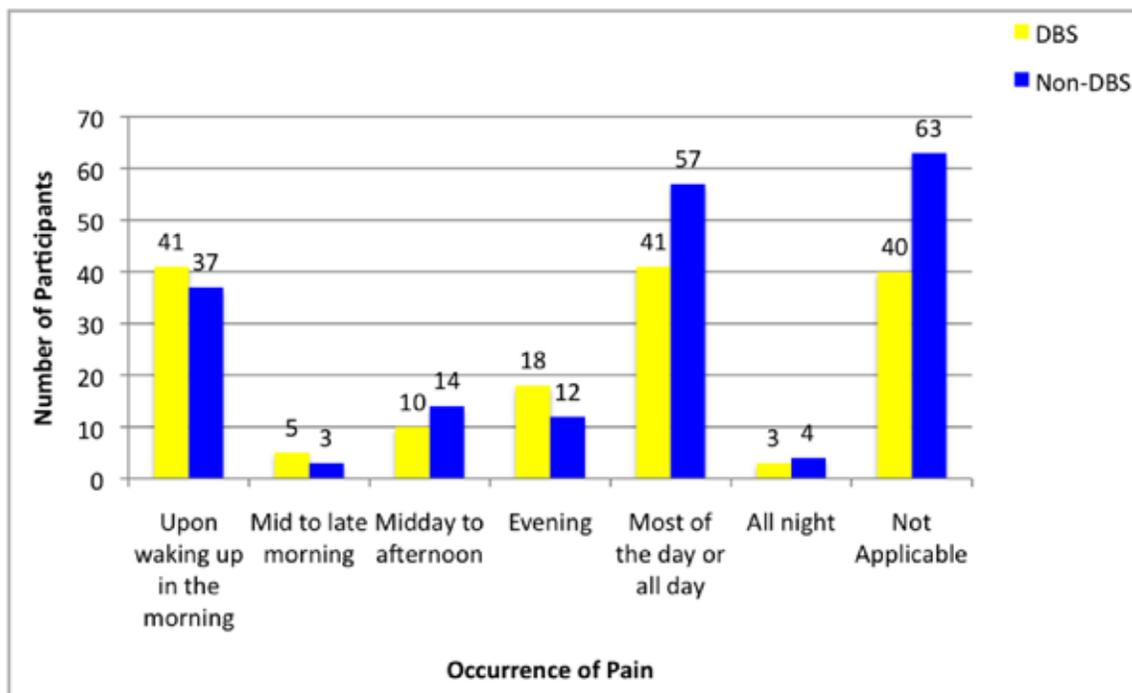
Severity Rating	% of DBS Participants	% of Non-DBS Participants
No pain	21%	18%
Mild	15%	18%
Discomfort	33%	31%
Distressing	25%	26%
Horrible	5%	6%
Excruciating	1%	1%

**Pain Occurrence:**

The majority of participants experienced pain upon waking up in the morning, or most/all of the day (See Figure 3).

- 34% of the **DBS group** and 29% of the **Non-DBS group** experienced pain upon waking in the morning.
- 34% of the **DBS group** and 45% of the **Non-DBS group** experienced pain most or all of the day.
- Fewer participants stated that they predominantly felt pain during the mid to late morning, midday to afternoon, or evening.
- There was not a statistically significant difference between the two groups as it related to when they predominantly experienced pain.

Figure 3. The Time of Day when Pain is most Prevalent



**Common Locations of Pain:**

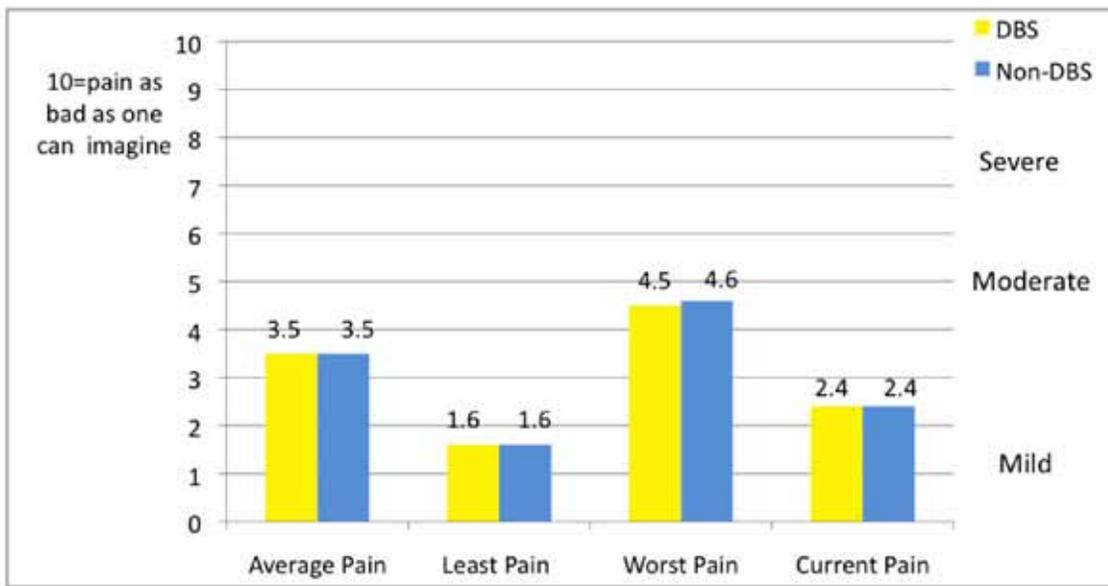
- For both the **DBS** and **Non-DBS groups**, the most commonly endorsed locations of pain included the lower back (53%), the neck (41%), and legs (31%).
- Between 20% and 30% of the participants rated having pain in the following anatomical locations: shoulders, left arm, feet, and mid back.

- Less than 20% of the participants endorsed experiencing pain in the following anatomical locations: upper back, hands, stomach, right arm, and head.

**Brief Pain Inventory:**

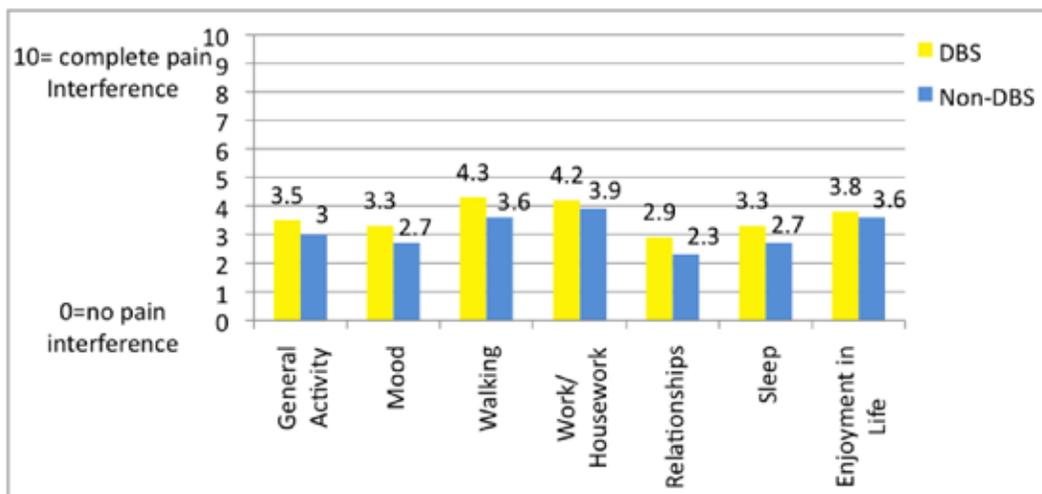
- There were similar pain ratings between the **DBS group** and **Non-DBS group** on the Brief Pain Inventory with the “average” rating of pain falling in the mild-to-moderate range; mild pain is rated as 1 to 3, moderate pain is rated as 4 to 7, and severe pain is rated as 8 to 10 (see Figure 4).
- The two groups had similar pain relief from treatment/medication.
- The two groups reported similar levels of pain interference in life-related variables.

**Figure 4. Pain Ratings on the Brief Pain Inventory: Ratings Representing Pain Levels within a 24 Hour Period.**



For the **DBS group**, the average rating for the amount of relief that the participants experienced from pain treatment or medications was a 5.0 (0=no relief; 10=complete relief). A comparable rating was found for the **Non-DBS group**, which was a rating of 5.3.

**Figure 5. Level of Pain Interference in Some Activities of Daily Living.**



On a scale assessing to what extent the participants' pain interfered with activities of daily living (0=does not interfere; 10=completely interferes), it was evident that 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. As seen in Figure 5, the participants rated the interference in the aforementioned variables as ranging between the upper end of mild interference to lower end of moderate interference.

An overall "pain interference" score was calculated by creating a total score for the ratings related to pain interfering with general activity, mood, walking ability, normal work or housework, relations with others, sleep, and enjoyment in life. The overall rating of pain interference was not significantly different for the **DBS group** and **Non-DBS group**.

### Characteristics of the Pain Experience:

- There was no difference in how the **DBS group** and **Non-DBS group** characterized pain.
- Over 50% of the participants in each group described their pain as cramping, aching, and tiring/exhausting, with the former two descriptors being related to sensory descriptions (physical descriptors), while the descriptor "tiring/exhausting" can be classified as more affective (emotional).
- Between 35% and 50% of both groups characterized their pain symptoms as sharp and tender.
- Between 25% and 35% of the participants in both groups characterized their pain symptoms as throbbing, shooting, stabbing, hot/burning, and heavy.
- Less than 25% endorsed the pain descriptors of gnawing and splitting.
- Less than 25% of each group described their pain as punishing, fearful, or sickening.

### Younger versus Older Groups:

Since both the **DBS** and **Non-DBS group** were comparable as it related to the experience of pain, the following analyses incorporated both the **DBS** and **Non-DBS groups** "together," while dividing the participants into two age groups. The participants were divided into a "**Younger PD group**" and an "**Older PD group**", 50 to 69 years and 70 years and older, respectively.

- There were similar pain ratings for the **Younger** and **Older PD** groups.
- There was a similar rating for pain interference for both the **Younger** and **Older PD** groups.
- The majority of both groups attributed pain to musculoskeletal pain.
- The **Older PD** group reported more radicular and neuritic pain (see Table 3 for definitions) than the **Younger PD group** (statistically significant).

The **Younger PD group** reported an average pain level of 3.61 (0=no pain; 10=pain as bad as one can imagine), and the **Older PD group** reported an average pain level of 3.27. These ratings are both in the mild-to-moderate pain range and not significantly different. An overall "pain interference" score was calculated by creating a total score for the ratings related to pain interfering with general activity, mood, walking ability, normal work or housework, relations with others, sleep, and enjoyment in life. The report of the overall rating of pain interference was not significantly different for the **Younger PD group** and the **Older PD group**.

Pain can be caused by a number of pain conditions. There are a number of common causes of pain for patients with PD (please refer to Table 3).

**Table 3. Common Causes of Pain in PD.**

1. <b>Musculoskeletal pain</b>	Aching muscles and joints, such as neck, hip, or back pain; shoulder stiffness/frozen shoulder.
2. <b>Radicular and neuritic pain</b>	Pain that occurs close to a nerve or nerve root, such as sciatica, which is inflammation or a compression in the low back area. Patients usually describe root pain as a sharp, lightning-like sensation that radiates towards the end of a limb.
3. <b>Pain associated with dystonia</b>	The pain arises from the severe, forceful, sustained twisting movements and postures that are called dystonia.
4. <b>Akathisia</b>	Restlessness; often being unable to sit still, lie in bed, drive a car, eat at a table or attend social gatherings because of the restlessness.
5. <b>Central pain syndromes</b>	Often described by patients as bizarre unexplained sensations of stabbing, burning and scalding. The pain can occur in unusual body distributions: the abdomen, chest, mouth, rectum or genitalia.

Table 4 shows the difference between the “**Younger PD group**” and an “**Older PD group**” as it relates to what the participants attribute their pain. The majority of both groups indicated that their pain was predominantly attributable to musculoskeletal pain. The main difference between the **Younger PD group** and the **Older PD group** was the attribution of pain to radicular and neuritic pain. A greater percentage of the **Older PD group** endorsed pain symptoms that were related to radicular and neuritic pain.

**Table 4. Percent of Participants Reporting the Perceived Cause of the Pain for the Younger and Older Groups**

Perceived Cause of Pain	Younger PD Group 50-69 years (n=230)	Older PD Group 70+ years (n=128)
Musculoskeletal pain	71%	64%
Radicular and neuritic pain*	23%	38%
Pain associated with dystonia	32%	23%
Akathisia	29%	23%
Central pain syndromes	13%	12%
Other pain symptoms	2%	3%
Not Sure	<1%	0%

\* Denotes significance between the two groups

### Pain as it Relates to “Early versus Advanced PD”

Previous research has found that in PD, the mean time from symptom onset to development of motor complications was 6 years.<sup>2,19</sup> 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.

- There were similar pain levels between **Early PD group** and **Advanced PD group**.
- The **Advanced PD group** has more pain interference than **Early PD group**.
- Both groups primarily attribute their pain to musculoskeletal pain.
- The **Advanced PD group** endorsed greater pain related to dystonia and akathisia.

The **Early PD group** reported an average pain level of 3.15 (0=no pain; 10=pain as bad as one can imagine), and the **Advanced PD group** reported an average pain level of 3.59 (on the same scale), which are in the mild-to-moderate pain range. The ratings between groups were not significantly different. As noted previously, an overall “pain interference” score was calculated by creating a total score for the ratings related to pain interfering with general activity, mood, walking ability, normal work or housework, relations with others, sleep, and enjoyment in life. The report of the overall rating of pain interference was significantly different between the **Early and Advanced PD groups**, with the **Advanced PD group** rating higher levels of pain interference with general life activity.

As noted previously, PD patients have been found to attribute their pain to a number of different conditions (see Table 3). Table 5 shows the difference between the “**Early PD group**” and an “**Advanced PD group**” as it relates to what the participants attribute their pain. Well over half of both groups indicated that the majority of their pain is attributable to musculoskeletal pain. A greater percentage of the **Advanced PD group**, when compared to the **Early PD group**, endorsed pain symptoms that were related to dystonia and akathisia.

**Table 5. Percent of Participants Reporting the Perceived Cause of the Pain for the Early PD and Advanced PD Groups**

Perceived Cause of Pain	Early PD Group <6 years (n=81)	Advanced PD Group 6+ years (n=273)
Musculoskeletal pain	62%	70%
Radicular and neuritic pain	25%	30%
Pain associated with dystonia*	14%	33%
Akathisia*	17%	30%
Central pain syndromes	11%	12%
Other pain symptoms	3%	2%
Not Sure	0%	0%

\* Denotes significance between the two groups

### Sinemet and Pain:

- Sinemet was perceived to be considered helpful in reducing pain for 38% of the **DBS group** and 35% of the **Non-DBS group**.
- Only 4 % and 2% of the **DBS** and **Non-DBS groups**, respectively, indicated that Sinemet worsened their pain.
- The remainder of the participants either did not endorse pain, or they indicated that Sinemet neither helped nor worsened their pain.

### Pain Management:

When considering all of the participants:

- 43% stated that they were currently engaged in treatment for pain

Of those receiving “pain management,” the following percentage of participants indicated that they received pain management from the designated clinician:

- 24% from a Neurologist
- 15% from a Primary Care Physician
- 15% from a Physical Therapist
- 5% from a Pain Specialist
- <1% from an Anesthesiologist
- 7% from a Massage Therapist
- 8% from a Chiropractor or Acupuncturist
- <1% from a Psychologist
- 5% from a Nurse Practitioner or Physician’s Assistant

### For those receiving treatment for pain:

- 98% indicated that treatment was helpful.

### Of those who stated that treatment was helpful:

- 12% stated that it was “a little bit” helpful
- 35% stated that it was “moderately” helpful
- 24% reported that it was “quite a bit” helpful
- 6% reported that it was “extremely” helpful

### Type of treatment for pain:

- Fifty-one percent of the participants receiving medications specifically for pain indicated that the medications were helpful.
- Out of the common interventions for pain, including medications, stretching, exercise, massage, acupuncture, psychotherapy, nutrition, and other (e.g., ice and heat, laying down), medications and exercise were deemed the most helpful in treating pain symptoms.

## Summary of Key Findings

- 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.

- The most commonly endorsed locations of the pain in the body included the lower back (53%), the neck (41%), and the legs (31%).
- When asked about the daily experience of pain, the majority of the participants stated that pain tends to occur in the morning or all or most of the day.
- 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.
- The participants were divided into a **Younger PD group** and an **Older PD group**, 50 to 69 years and 70 years and older, respectively.
  - The overall rating of pain and pain interference were not significantly different for the **Younger PD group** and the **Older PD group**.
  - The majority of both groups indicated that their pain was predominantly attributable to musculoskeletal pain. The only difference between the **Younger PD group** and the **Older PD group** related to the experience of radicular and neuritic pain. In both groups, radicular and neurotic pain was common, but it was endorsed in greater frequency in the older group.
- 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 based on previous research.
  - There was not a significant difference of overall pain ratings between the **Early** and **Advanced PD groups**.
  - The overall rating of pain interference was significantly different between the **Early** and **Advanced PD groups**. The **Advanced PD group** rated higher levels of pain interference on general life activity.
  - Both **groups** indicated that the majority of their pain was attributable to musculoskeletal pain. There was one significant difference between the **Early PD group** and the **Advanced PD group**. A greater percentage of the **Advanced PD group** endorsed pain symptoms that were related to dystonia and akathisia.
- In the context of pain being prevalent in this population, many individuals who endorsed pain were not receiving treatment for it. The vast majority of pain treatment recipients, however, perceived treatment as helpful. The participants in this study indicated that the most helpful interventions for pain were medications and exercise.

## Concluding Remarks

- Pain in PD is complex. It is clear that pain in PWP is prevalent, under-assessed, and undertreated, having a pervasive psychosocial impact on patients and their families.
- As Ford<sup>12</sup> indicated, the “most important diagnostic tool in managing pain in PD is the patient’s history” or narrative of the experience of painful symptoms. Pain is subjective, difficult to describe and poorly understood in PWP. Even though most of the participants in this study experienced pain, many have not received treatment for it. Understanding the perspective of the person with PD, as it relates to pain, is imperative in the quest to better understand pain and the relationship of pain related to PD, and to move toward state of the art pain assessment and treatment.
- Better definitions of and understanding of pain that PWP experience need to be established, particularly in the context of pain directly related to PD and pain that is experienced in PWP that is related to other medical conditions.
- Clinical research has shown that pain may be one of the earliest symptoms that PWP may experience, even before a full diagnosis of PD is made. It is clear that more research needs to be completed to better understand

the non-motoric complication and relationship to the dopamine system.

- Musculoskeletal pain was highly reported in this study, particularly in the back and neck. The assessment of pain as it relates to the impact of PD on the musculoskeletal system (e.g., postural changes) is indicated, and more aggressive treatment in this regard may be of benefit.
- In the context of the current findings, one could hypothesize that as PD progresses, pain interferes with general life activity in greater levels when compared to those whose symptoms have not developed into significant motor complications, regardless of the age of the individual. Thus, pain assessment at various time points during the progression of the disease is indicated. Additionally, education about and implementation of non-medication approaches to preventing pain and/or managing pain is warranted.
- 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 may find relief from an appropriate medication regimen to treat pain and an exercise program.
- 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.

## Acknowledgements

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