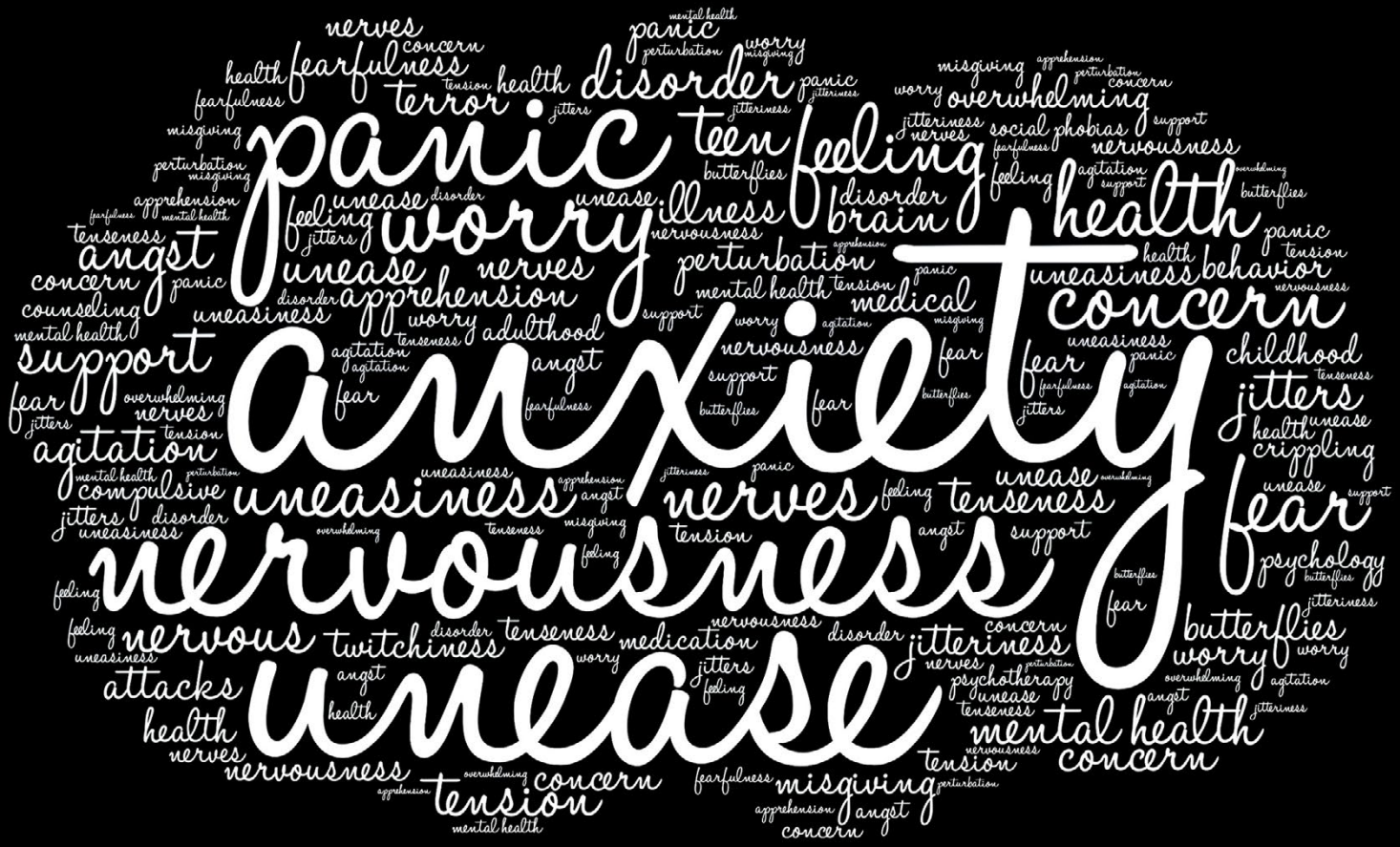
PARKINSONALLIANCE

Fall 2018



Anxiety & Parkinson's Disease: The Patient's Perspective

INTRODUCTION

Anxiety Defined[1]:

Anxiety Symptoms: excessive worry, apprehension or nervousness.

- Anxiety can be experienced in numerous ways including feeling worried and concerned, overwhelmed, restless, keyed up or on edge, or irritable, or ruminating on matters that result in anxiety.
- Anxiety can be experienced through physical symptoms (called somatic symptoms), such as autonomic arousal (sweating, dizziness, shortness of breath, increased heart rate), fatigue, muscle tension/aches, shakiness (different than a typical PD tremor), distraction, and sleep disturbance.
- Anxiety can present as having a specific phobia or fear (i.e., afraid of social settings, large crowds, enclosed spaces, being in areas that cause anxiety), separation anxiety, obsessive thoughts and compulsive behaviors, stress related to trauma, and panic or anxiety attacks.

Anxiety Disorder: When anxiety, worry, or physical symptoms (due to anxiety) cause significant distress or impede social, occupational, or other important areas of functioning. There are specific criteria for anxiety disorders that specialists use for classification.

Overview:

Over 200 years ago James Parkinson noted that anxiety appeared to be a nonmotor symptom in Parkinson's disease[2]. Research estimates that between 25% and 43% of individuals with PD have an anxiety disorder[3-6]. The types of anxiety disorders common among this population vary, though common experiences include generalized anxiety, panic attacks, and social phobia and agoraphobia (fear and avoidance of places or situations that might cause panic or feelings of being trapped, helpless, or embarrassed), as many individuals with PD develop increased fear of social judgment, stigma, and fear of sudden symptom onset and mobility difficulties outside the home [3,4,6]. While some may argue that more severe PD symptoms are likely causes of anxiety, research indicates that the relationship is bidirectional and increases in anxiety symptoms are, in themselves, contributory factors to reduced quality of life among individuals with PD[7-9].

Prevalence:

A 2010 study found that approximately 25% of individuals with PD in a randomly selected sample met criteria for an anxiety disorder, which was higher than prevalence rates in previous studies[10-12]. This finding was consistent with other research that estimated the prevalence to be approximately 27% [4,13]. There is also evidence that up to 67% of individuals with PD, though not diagnosed with anxiety disorders per se, experience clinically significant symptoms of anxiety[14]. The presence of anxiety is associated with severity of PD symptoms and worse quality of life. Research has found that younger individuals have been found to be more likely to have anxiety, while there was not a significant difference in gender[3].

Causes of Anxiety in PD:

Anxiety can be caused by both reactions to a situation or to biological factors. While much research has focused on the reactionary nature of anxiety in PD (e.g., worry about progression of PD and what the future holds; fear of falling), some studies have explored the role of neurochemical changes in PD that may be related to increased symptoms of anxiety[15]. An expanding body of research has even theorized that anxiety may, in fact, represent an early PD symptom (i.e., even before diagnosis) and be inherent to the PD syndrome itself [16-18]. There is emerging evidence that changes in dopamine and alterations in other neurochemicals for individuals with PD is associated with anxiety in PD [19-22, 15].

Somatic (physical symptoms) vs. Psychic (psychological symptoms):

One of the factors that makes the understanding of anxiety and PD complex is the fact that somatic features of anxiety overlap with common symptoms of PD, including autonomic dysfunction (e.g., heart racing and lightheadedness), fatigue, muscle tension, sleep disturbance, distractibility, and trembling[23]. Many existing anxiety scales rely heavily on the assessment of somatic symptoms, which may complicate accurate diagnosis and conceptualization, and consequently result in under-identifying or overreporting anxiety for individuals with PD.

Common psychological symptoms of anxiety in the PD population include excessive worry, restlessness, social anxiety, with a social phobia prevalence rate of approximately 30%[21,24,25] and obsessive thinking and compulsive behaviors, also called obsessive-compulsive symptoms[26].

Treatment:

Regarding treatment for anxiety, medications are commonly the first intervention to come to mind. Although medications for anxiety can be helpful for individuals with PD, non-medication intervention independent of or in conjunction with medication can also be helpful. Research studies have found that cognitive-behavioral therapy (CBT) is an effective treatment for anxiety for People with Parkinson's (PWP) [27,28]. Cognitive-behavioral therapy is a form of psychotherapy that emphasizes 1. the relationships between thoughts, feelings, and behaviors and 2. a collaborative approach between patient and psychotherapist to proactively implement healthy ways to cope with life's difficulties. Mindfulness-based therapy has been proven effective[29]. Exercise[30], yoga[31], and acupuncture [32] have also been found to help reduce anxiety.

As for medications, benzodiazepines, buspirone and selective serotonin reuptake inhibitor (SSRIs) and related antidepressants (e.g., Paxil, Lexapro, Zoloft and Effexor) have been clinically evaluated for effectiveness in treating anxiety among individuals with PD[33-37]. Though such medications can be effective, benzodiazepines present numerous risk factors, particularly for PD patients, including excessive tiredness, cognitive difficulties, and increased risk of gait/balance problems and falls[38]. There is limited research on the effectiveness of SSRIs on anxiety specifically among PD patients, though the data from uncontrolled studies is promising[35-37] .

In summary, neuroscientists and clinicians specializing in PD are learning 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. Understanding the patient's perspective about his or her personal experience of anxiety has important implications.

OBJECTIVES

- To learn about the patients' perspective about symptoms of anxiety.
- To understand the prevalence of the impact of anxiety on daily life experiences.
- To understand the extent people with PD perceive themselves as having undergone assessment of and treatment for anxiety.

METHODS

- Participants were recruited from prior survey participation that was conducted by The Parkinson Alliance (PA), announcements at PD support groups, announcements in medical clinics, and The PA website.
- A focus of The Parkinson Alliance is to better understand experiences for individuals with Deep Brain Stimulation (DBS) and those without Deep Brain Stimulation (Non-DBS). There were 1,173 individuals who participated in this survey, including 320 participants with PD who underwent **DBS** and 853 individuals with PD without DBS (**Non-DBS group**; see Table 1 for demographics and clinical features).
- For both the **DBS group** and **Non-DBS group,** approximately 88% completed their survey independently, whereas, 12% of participants required assistance.
- Participants represented 50 states, with California (12%), New Jersey (9%), New York (8%), Texas (8%), Florida (7%), Arizona (7%), Colorado (3%), Pennsylvania (4%), Virginia (2%), and Minnesota (2%) being the states with the most participants. There were 31 international participants.

Measures: **1.** The Demographic Questionnaire with additional questions related to anxiety (i.e., perceived anxiety severity; assessment and treatment of anxiety); 2. The Parkinson Anxiety Scale[13]; 3. a questionnaire assessing the impact of anxiety on everyday life:

The Demographic Questionnaire:

- The self-report questionnaire inquired about basic demographic information (e.g., sex status, marital status, education) as well as pertinent clinical information (e.g., perceived severity of anxiety; engagement in assessment and treatment for anxiety).

Parkinson Anxiety Scale[13]:

- The scale consists of three subscales: one pertaining to persisting anxiety (5 items), one to episodic anxiety (4 items), and one to avoidance behavior (3 items). The total number of items is 12. Items are scored on a 5-point Likert scale, with "0" meaning "none or never" and "4" meaning "severe or almost always." There is a maximum total score of 48. Higher scores indicate great experiences of anxiety.

Impact of Anxiety on Everyday Life (assessment instrument developed by The Parkinson Alliance)

- This self-report questionnaire has 10 questions to investigate how anxiety impacts everyday life. Questions related to "day-to-day functions," such as fear of falling, relationships with others, social engagement, engagement in hobbies/leisure activities, engagement in volunteer activities or work, health status, and overall "quality of life."
- Each item was rated on a 5-point scale ranging from "0" meaning "not at all" to "4" meaning "extremely/completely," with the option of indicating "not applicable" on select items. Higher scores indicate a greater impact of anxiety on everyday life.

Comparisons based on age and disease duration groups:

- Age: There were 24 participants who were under age 50 (the youngest PD group). Age groups were further divided into a **Younger PD group** (ages 50-69 years of age) and an **Older PD group** (ages 70+ years).
- Disease Duration: In previous research pertaining to individuals with PD, the average time from symptom onset to development of motor complications was 6 years. Previous research has divided groups into **Early Stage (<6 years)** and **Advanced Stage PD (6+ years)** to define a valid partition between early and advanced disease states[39,40]. To better illustrate the impact of disease duration on anxiety variables in individuals with PD, the **Advanced Stage PD group** was further divided into **Early Advanced Stage PD (6-10 years)** and **Late Advanced Stage PD (11+ years)**.
- The results will be presented using the entire sample and groups matched on age (Younger PD and Older PD groups) and disease duration.

Factors to consider when interpreting the results:

- This study used a survey-based methodology. Generalizability of the results may be limited. Sample sizes noted in the sections below may vary somewhat within specific groups (e.g., younger, older, early, advanced, etc.), since some individuals may not have responded to a specific question. Research has found that some individuals with PD, particularly as cognition becomes more severely impaired, may have reduced insight/awareness into or appreciation of their difficulties[41], a factor warranting consideration when interpreting self-report questionnaires. Importantly, the subjective report in this survey serves to highlight the "patient's perspective" about his or her experience with anxiety.

RESULTS

The summary of the demographic information and clinical characteristics of the participants in this study can be found in Table 1. The **Non-DBS group** was numerically older than the **DBS group (average: 71 versus 67 years, respectively).** By contrast, the **DBS group** had a significantly younger average age at PD diagnosis **(51 years)** than the **Non-DBS group (63 years)** and a longer duration of PD (see Table 1). Sex (male greater than female), marital status (the majority being married), race (the majority being White/Caucasian), and education (the majority having higher education) were comparable between groups.

Table 1. Demographics and Clinical Features of the Sample

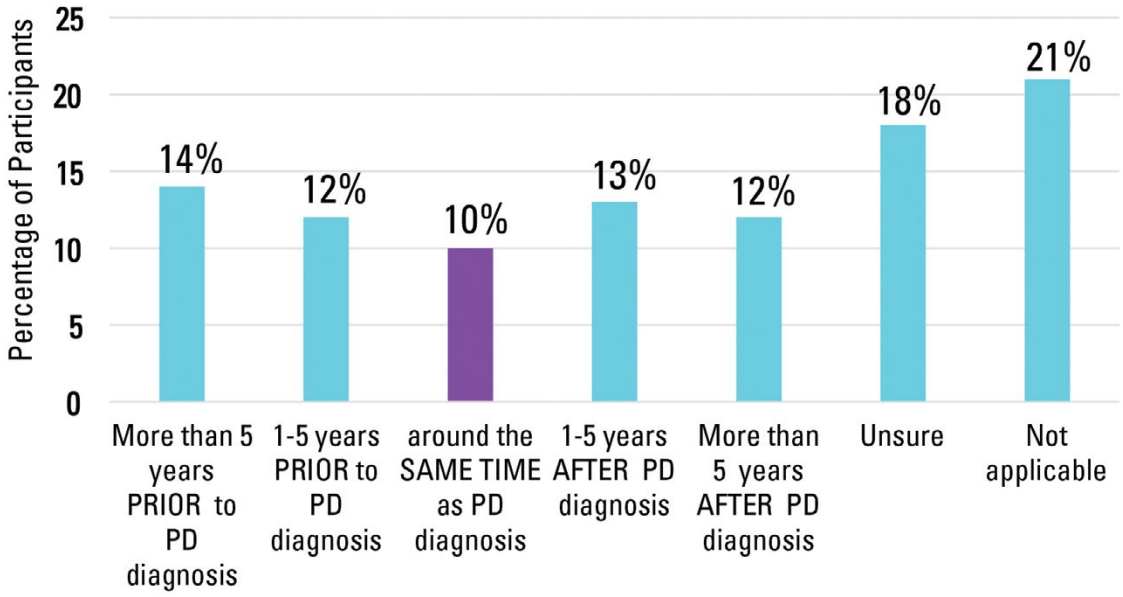
	DBS (*n* =320)	**Non-DBS (*n* =853)**
Average Age in Years (range)	67 (45-90)	71 (39-97)
Duration of PD in Years (range)*	16 (3-41)	8 (0-34)
Average Age of PD Diagnosis (range)*	51 (21-75)	63 (23-94)
Average Age at Time of DBS in Years (range)	60 (32-83)	n/a
Average Duration since DBS in Years (range)	7 (0-29)	n/a
Target: STN	49%	n/a
GPi	8%	n/a
Not Sure	43%	n/a
Male	55%	54%
Female	45%	46%
Married	81%	79%
Lives Alone	20%	25%
Race		
Caucasian	95%	95%
Latino/Hispanic	3%	3%
African American	< 1%	<1%
Asian	1%	1%
American Indian	<1%	<1%
Native Hawaiian or Pacific Islander	<1%	<1%
Other	<1%	<1%
Education		
<12 years	6%	5%
High School	7%	4%
Some College or Associate's Degree	15%	14%
College	22%	20%
Graduate/Advanced Degree	50%	57%

* Clinically significant difference between groups
n/a = not applicable

PERCEIVED ONSET OF ANXIETY: PERCEPTION OF THE PARTICIPANT

- At the time of this survey, a considerable number of participants experienced anxiety early in their disease course, even prior to their PD diagnosis (see Figure 1).
  - 26% experienced anxiety before PD diagnosis
  - 10% experienced anxiety around the time of PD diagnosis
  - 25% experienced anxiety following PD diagnosis and as the PD progressed
  - 18% were not sure when anxiety began
  - 21% have not experienced anxiety

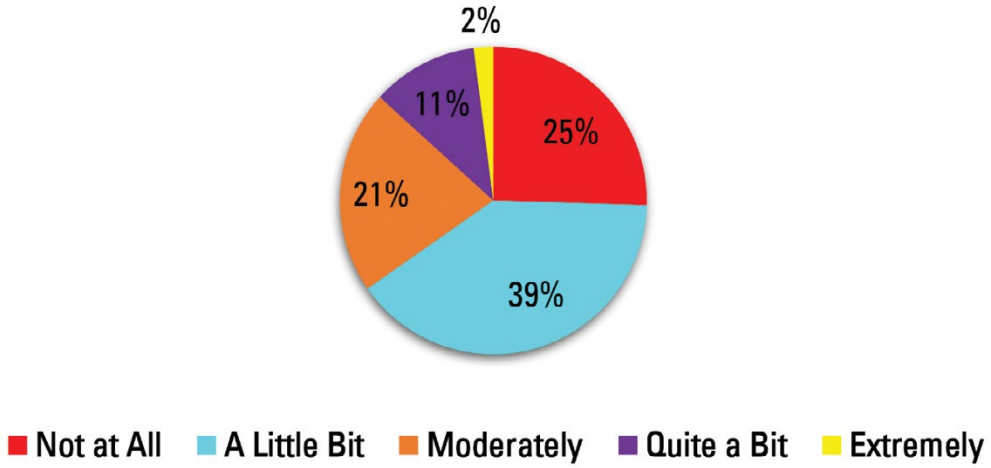
Figure 1. Perceived Onset of Anxiety Related to Time of PD Diagnosis (N = 1,130)



CURRENT STATUS OF ANXIETY:

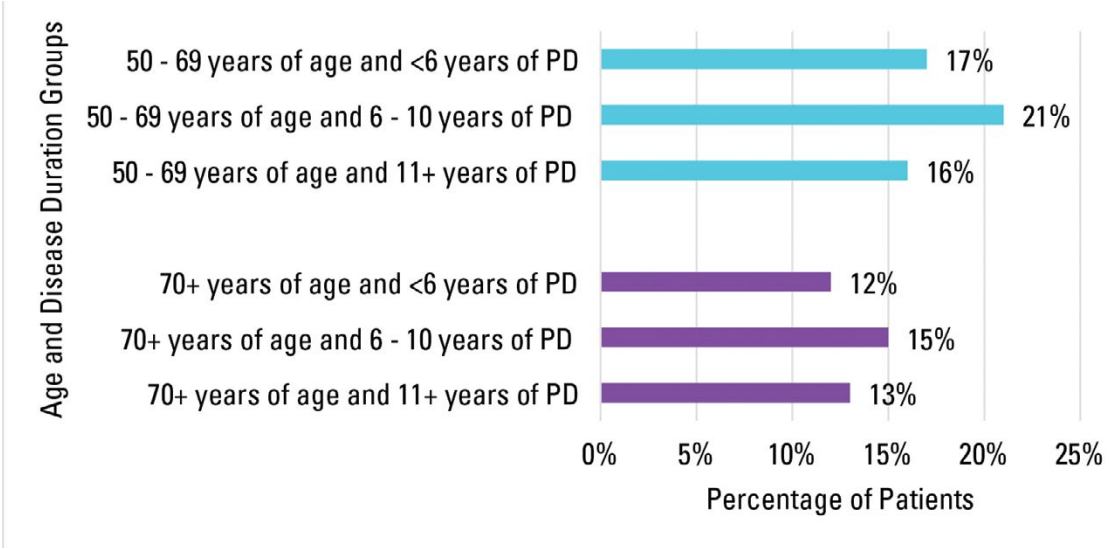
- When asked to what extent the participants experience anxiety (on average) within the last seven days (N=1,146), 30% of the participants ranged between "moderately" and "extremely" (see Figure 2).
- For those who reported anxiety, anxiety was reported to be worse during the afternoon and night, as compared to the morning and midday.
  - Anxiety in the morning: 11% of the participants
  - Anxiety in midday (around noon): 10% of the participants
  - Anxiety in the afternoon: 19% of the participants
  - Anxiety in the evening and during the middle of the night: 60% of the participants

Figure 2. Percentage of participants reporting generalized anxiety (N = 1,146)



- When asked about the percentage of participants who have been diagnosed with anxiety by a mental health professional (e.g., psychiatrist; psychologist), the **Younger PD group** (50-69 years of age) had a greater number of individuals who reported being diagnosed with anxiety, as compared to the **Older PD group** (70+ years), see Figure 3. When looking at disease duration, the **6-10 year group** had a larger percentage of individuals who have been diagnosed with anxiety for both **Younger** and **Older PD groups**, when taking into account age.

Figure 3. Percentage of PD patients diagnosed with Anxiety by age and disease duration groups (N=1,130)



<u>THE PARKINSON ANXIETY SCALE</u> (see Table 2):

- Over half of the participants across age and disease duration cohorts reported "very mild" to "mild" levels of anxiety within each anxiety domain: Persistent Anxiety, Episodic/Panic Anxiety, and Avoidant Anxiety.
  - The "Persistent" Anxiety category was more frequently reported by participants as compared to "Panic" or "Avoidant" Anxiety.
  - <u>Persistent Anxiety:</u> Between 12% and 20% of the participants reported experiencing moderate to severe persistent anxiety.
  - Episodic/Panic <u>Anxiety:</u> Between 3% to 4% of the participants experience moderate to severe panic anxiety.
  - <u>Avoidant Anxiety:</u> Between 4% to 8% of the participants experience moderate to severe avoidant anxiety.
- **There was not a significant difference in anxiety between DBS and Non-DBS PD groups.**
- Anxiety levels were significantly different between **male** and **female** participants, with females reporting more anxiety.
- Anxiety levels were significantly different between those participants **living alone** as compared to those who **do not live alone**, with those who live alone reporting a greater degree of anxiety.

IMPACT OF ANXIETY ON EVERYDAY LIFE (see Table 3):

- Across age and disease duration groups, a high percentage of participants reported that anxiety adversely impacts day-to-day functions.
  - 26% to 34% reported that anxiety had a "moderate" to "extreme" impact on day-to-day function in general.
- 19% to 41% of the participants in this survey, reported that anxiety has a "moderate" to "extreme" impact on everyday activities, such as walking and standing up (fear of falling), relationships with others, social engagement, engagement in hobbies/leisure activities, engagement in volunteer activities or work, health status, and overall "quality of life."
- The impact of anxiety on every-day life was greater as age and disease duration increased.

Table 2. Parkinson's Anxiety Scale

	Early PD Group (<6 years duration)		Advanced PD Group 6-10 years duration		Advanced PD Group 11+ years duration	
	Younger (50-69) (n =135-137)[1]	Older (70+) (n=163-167)[1]	Younger (50-69) (n =136-139)[1]	Older (70+) (n=197-200) [1]	Younger (50-69) (n=189-192) [1]	Older (70+) (n =222-232) [1]
Persistent Anxiety Average						
Not at all	21%	23%	12%	17%	13%	17%
Very Mild/Mild	59%	62%	71%	71%	67%	69%
Moderate	17%	14%	14%	12%	18%	14%
Severe	3%	1%	3%	<1%	2%	0%
Panic Anxiey Average						
Not at all	39%	38%	37%	33%	29%	31%
Very Mild/Mild	58%	58%	59%	64%	67%	65%
Moderate	3%	4%	4%	3%	3%	4%
Severe	0%	0%	0%	0%	<1%	0%
Avoidance Anxiety Average						
Not at all	28%	27%	21%	28%	17%	19%
Very Mild/Mild	65%	69%	71%	66%	75%	75%
Moderate	5%	3%	6%	6%	6%	5%
Severe	0%	1%	2%	0%	2%	<1%

1. The range represents the different number of respondents across domains.
2. The percentiles may not add to 100, as the percentile not reported (missing items) reflects the number of participants who did not respond to the questions.

Table 3. Impact of Anxiety on Every Day Life: The patient's perspective

	Early PD Group (<6 years duration)		Advanced PD Group 6-10 years duration		Advanced PD Group 11+ years duration	
	Younger (50-69) (n =139-143)[1]	Older (70+) (n=169-172)[1]	Younger (50-69) (n =137-139)[1]	Older (70+) (n=197-199) [1]	Younger (50-69) (n=192-195) [1]	Older (70+) (n =222-232) [1]
Impacts day-to-day functions						
Not at all/A Little Bit	72.4%	74.1%	67.6%	69.2%	65.6%	68.9%
Moderately	18.1%	16.5%	19.4%	21.2%	23.1%	19.8%
Quite a Bit/Extremely	8.0%	8.8%	10.8%	9.1%	11.2%	9.1%
Occurs when walking						
Not at all/A Little Bit	78.4%	73.1%	69.6%	67.3%	57.9%	57.1%
Moderately	9.4%	16.4%	18.8%	15.6%	19.0%	19.6%
Quite a Bit/Extremely	10.1%	9.9%	10.9%	16.1%	23.1%	19.6%
Occurs when getting out of a seated position						

Not at all/A Little Bit	79.2%	76.0%	76.6%	69.8%	68.9%	63.8%
Moderately	12.2%	14.0%	12.4$	16.6%	13.0%	18.3%
Quite a Bit/Extremely	6.5%	9.9%	10.2%	12.5%	18.1%	15.2%
Affects relationship with significant other						
Not at all/A Little Bit	65.7%	72.7%	67.9%	63.6%	59.5%	63.4%
Moderately	13.1%	10.5%	13.9%	20.7%	15.4%	14.3%
Quite a Bit/Extremely	13.1%	8.8%	7.3%	5.5%	16.9%	9.8%
Affects social engagement						
Not at all/A Little Bit	70.6%	73.7%	58.3%	67.2%	56.8%	63.8%
Moderately	11.5%	18.7%	22.3%	20.7%	19.8%	22.3%
Quite a Bit/Extremely	7.2%	7.6%	18.7%	11.1%	22.9%	11.6%
Results in feeling isolated						
Not at all/A Little Bit	73.4%	76.5%	63.3%	74.1%	60.8%	62.8%
Moderately	9.4%	15.3%	15.1%	14.2%	22.2%	22.4%
Quite a Bit/Extremely	6.5%	7.7%	20.8%	10.1%	17.0%	13.0%
Impacts ability to engage in leisure activities						
Not at all/A Little Bit	70.5%	76.6%	62.3%	71.7%	59.3%	61.7%
Moderately	15.1%	13.5%	21.0%	13.6%	16.0%	20.3%
Quite a Bit/Extremely	12.4%	9.3%	16.6%	12.6%	24.3%	14.5%
Impacts ability to participate in volunteer activities or work						
Not at all/A Little Bit	67.4%	69.8%	54.0%	61.8%	47.9%	52.3%
Moderately	10.9%	8.9%	15.8%	10.1%	19.6%	14.4%
Quite a Bit/Extremely	14.5%	11.2%	23.0%	15.0%	22.0%	16.7%
Impacts health status						
Not at all/A Little Bit	75.5%	80.6%	78.7%	79.3%	72.3%	69.2%
Moderately	10.1%	9.4%	11.0%	10.6%	15.9%	18.6%
Quite a Bit/Extremely	12.2%	8.8%	8.8%	8.6%	10.8%	8.6%
Impacts quality of life						
Not at all/A Little Bit	66.9%	73.5%	60.1%	65.0%	59.8%	56.7%
Moderately	14.4%	15.9%	19.6%	21.8%	19.6%	27.7%
Quite a Bit/Extremely	15.9%	19.4%	18.8%	12.7%	20.7%	14.3%

1. The range represents the different number of respondents across domains.
2. The percentiles may not add to 100, as the percentile not reported (missing items) reflects the number of participants who did not respond to the questions.

ASSESSMENT AND TREATMENT OF ANXIETY (N = 1,173)

- Less than 21% of individuals reported having been given a diagnosis of anxiety.
- Of those who have been formally assessed, participants reported a formal anxiety assessment was performed by the following specialists:
  - PCP or internist: 14%
  - Neurologist: 16%
  - Psychiatrist: 16%
  - Psychologist: 8%
  - Social Worker: 8%
- 21% reported having received education about the relationship between anxiety and PD
- 26% reported having participated in treatment with a psychiatrist

- 13% reported being under the care of a psychiatrist currently

- 35% reported having participated in treatment with a mental health provider who was not a psychiatrist.
  - 14% reported being in psychotherapy currently
- 29% reported taking medication for anxiety
  - Types of medications reportedly used (current or past use) are documented in Table 4.

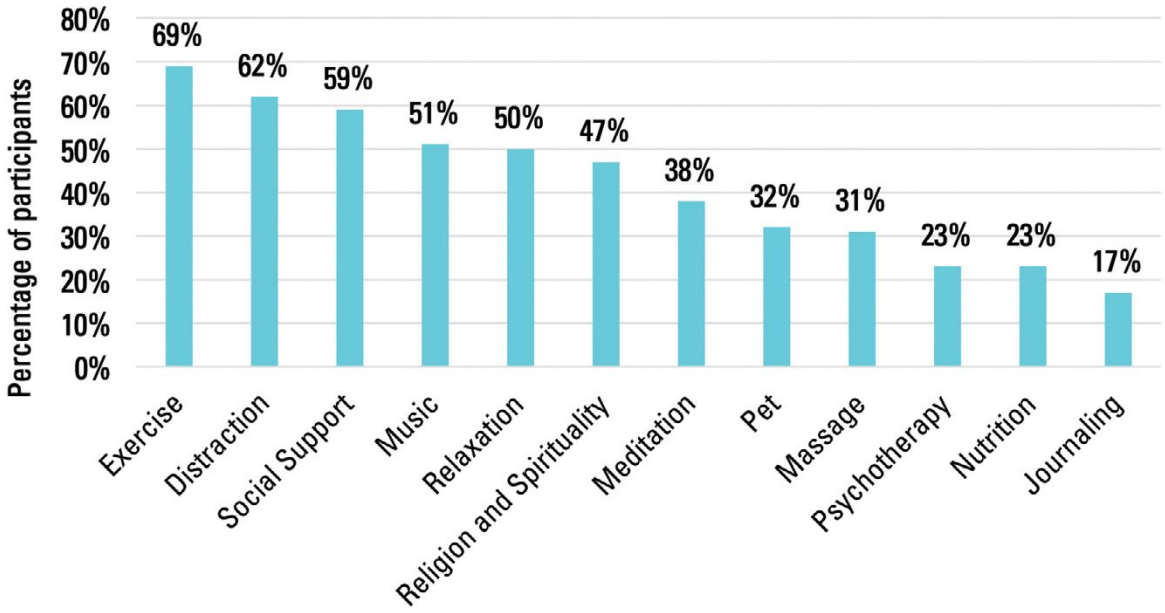
Table 4. Common medications prescribed for anxiety (N = 1,173)

Medication	Current Use	Past Use	Do Not Know
Beta Blockers	5%	4%	3%
Benzodiazepines			
Ativan	2%	5%	2%
Valium	1%	7%	1%
Klonopin	10%	6%	2%
Xanax	4%	6%	2%
Serax	<1%	<1%	2%
Selective Serotonin Reuptake Inhibitors (SSRIs)			
Lexapro	4%	5%	2%
Prozac	1%	6%	2%
Zoloft	6%	5%	2%
Paxil	2%	4%	2%
Luvox	<1%	<1%	2%
Celexa	3%	3%	2%
Selective Norepinephrine Reuptake Inhibitor (SNRI)			
Cymbalta	2%	2%	2%
Effexor	3%	3%	2%
Pristiq	<1%	<1%	2%
Tricyclic Antidepressants			
Pamelor	<1%	<1%	2%
Elavil	<1%	2%	2%
Tofranil	--	<1%	2%
Other			
Nardil	--	<1%	2%
Wellbutrin	4%	5%	2%

- To what extent are/were the medications perceived to be helpful? (N = 796)
  - 6% reported “not at all”
  - 14% reported “a little bit”
  - 16% reported “moderately”
  - 18% reported “quite a bit”
  - 5% reported “extremely”
  - 9% reported “do not know”
  - 32% “not applicable”

- 25% reported that a provider has recommended non-medication-based treatment of anxiety (N = 1,173)
- Many participants of this study reported engagement in non-medication-based anxiety treatments (see Figure 4).
    - Exercise, distraction techniques, social support, music, and relaxation techniques were coping strategies used by at least half of the participants in this survey.

Figure 4. Non-Medication based Anxiety Treatment (N = 324- 462) — Coping Techniques for Anxiety



SUMMARY AND DISCUSSION

Over 200 years ago James Parkinson noted that anxiety appeared to be a nonmotor symptom in Parkinson's disease[2]. Research estimates that between 25% and 43% of individuals with PD have an anxiety disorder[3-6]. The types of anxiety disorders common among this population vary, though experiences include generalized anxiety, panic attacks, and social phobia and agoraphobia (fear and avoidance of places or situations that might cause panic or feelings of being trapped, helpless, or embarrassed)[3,4,6]. While some may argue that more severe PD symptoms are likely causes of anxiety, research indicates that the relationship is bidirectional and increases in anxiety symptoms are, in themselves, contributory factors to reduced quality of life among individuals with PD[7-9].

TAKE HOME POINTS FROM THIS SURVEY:

Objective 1: To learn more about the patient's perspective about the experience of anxiety.

Anxiety in PD:

- Anxiety is highly prevalent for individuals with PD.
- 26% of the participants in this survey reported that anxiety was present prior to the diagnosis of PD.
- 35% of the participants reported experiencing "moderate" or "extreme" generalized anxiety.
- On a standardized measurement assessing subtypes and severity of anxiety:
    a. >50% of the participants across age and disease duration cohorts reported "very mild" to "mild" levels of anxiety within each anxiety domain: Persistent Anxiety, Episodic/Panic Anxiety, and Avoidant Anxiety.

b. The "Persistent Anxiety" was reported in much greater frequency than "Episodic/Panic" or "Avoidant" types of anxiety.

c. Persistent Anxiety that was characterized as moderate to severe occurred between 12% and 20% of the participants. In contrast, 3 to 4% of the participants experience moderate to severe episodic/panic anxiety, and 4 to 8% of the participants experience moderate to severe avoidant anxiety.

d. Females reported a greater degree of anxiety than males.

e. Those who live alone reported a greater degree of anxiety than those who lived with someone.

- Anxiety appears to be worse at night, when compared to other parts of the day.

Objective 2: To understand the prevalence of the impact of anxiety on daily life experiences.

- Across age and disease duration groups, a high percentage of participants reported that anxiety adversely impacts day-to-day functions. 26-34% reported that anxiety had a moderate to extreme impact on day-to-day functions in general.
- When asked about specific daily activities, 19-41% of the participants in this survey reported that anxiety has a moderate to extreme impact on everyday activities, including standing up and walking (fear of falling), relationships with others, social engagement, engagement in hobbies/leisure activities, engagement in volunteer activities or work, health status, and overall "quality of life".
- The impact of anxiety on every-day life increases as age and disease duration increase.

Objective 3: To understand the extent people with PD perceive themselves as having undergone assessment of and treatment for anxiety.

- Despite the high percentage of individuals experiencing heightened anxiety, only 19% of individuals reported having been "formally assessed" for anxiety.
  - Neurologists, Psychiatrists, and Primary Care Physicians are the most commonly reported specialties completing the assessment of anxiety.
- 29% reported taking medications for anxiety, with the majority experiencing at least some benefit of the medication. It appears, however, that despite medications being prescribed for anxiety, it is less common for individuals to undergo a formal assessment of anxiety, which may result in limited understanding of anxiety symptoms and also limited discussion about treatment options.
- A large percentage of participants also engage in non-medication based intervention for anxiety, including relaxation, music, meditation and psychotherapy.
- **There is indication that anxiety is underassessed and undertreated, and education about symptoms of and treatment for anxiety remains a significant unmet need in the management of PD patients.**

GENERAL COMMENTS AND RECOMMENDATIONS:

1. Anxiety is highly prevalent in individuals with PD, and education about anxiety is indicated. Anxiety can result from both psychological factors (common fears and worries that are directly related to PD and life stressors) and biological factors (many of the neurochemicals involved with symptoms of PD can also directly relate to anxiety and depression). Given the complex and variable presentation of anxiety symptoms in PD, seeking education about anxiety and PD is recommended:

   a. Have a conversation about anxiety (psychological and biological contributions; physical and psychological symptoms of anxiety) and related treatments with a specialist in movement disorders (e.g., a neurologist, psychiatrist, neuropsychologist, psychologist who are familiar with PD).

   b. Multiple factors can contribute to symptoms of anxiety, such as sleep disturbance, fatigue, balance problems,

medications that exacerbate or induce symptoms of anxiety, and co-existing medical symptoms (i.e., cardiovascular, pulmonary). When these symptoms or conditions are effectively treated improvement in anxiety may also result. Talk to your doctor about treating these other symptoms that may be contributing to anxiety.

2. Cognitive-behavioral psychotherapy for individuals with PD (and treatment for family too, if appropriate) can be an effective treatment for anxiety, psychosocial stressors, and developing coping strategies.
3. Medications that facilitate psychological well-being, in conjunction with psychotherapy, may be helpful for participants who experience anxiety. However, caution is indicated when it comes to selecting certain medications, as some medications (e.g., benzodiazepines, anticholinergic medications and dopamine agonists) can cause or worsen cognitive and psychological symptoms. It is recommended that use of psychotropic medications be monitored by a specialist in PD.
4. Other non-medication-based intervention may be helpful in managing anxiety:
    a. Exercise
    b. Relaxation techniques
    c. Yoga
    d. Massage Therapy
    e. Acupuncture
    f. Aromatherapy
    g. Music therapy
    h. Animal-assisted therapy (i.e., pet therapy): an intervention becoming more popular to help individuals cope with and address health problems and symptoms.
        i. Service dogs trained to work with people with PD may help their owners maintain balance while walking, alert a family member after a fall, or relieve a freezing spell (e.g., by nudging a leg).
        ii. Having a pet and engaging in animal-assisted activities may have a more general purpose, such as providing companionship, comfort, and enjoyment, and creating meaning and purpose.
5. Using resources in the community, such as support groups, exercise groups, yoga classes, and public parks, can result in a favorable impact on physical, cognitive, and psychological well-being.

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