PARKINSONALLIANCE

Spring 2018

Vision and Parkinson's Disease: The Patient's Perspective

INTRODUCTION

Non-motor symptoms of Parkinson's disease (PD) are prevalent throughout the disease course and are now seen as dominant in the clinical picture of advanced PD, as such symptoms contribute to severe disability and reduced quality of life[1,2]. Vision changes, manifesting with non-motor subjective symptoms and physical signs, can occur in many individuals with PD; there have been reports that the prevalence of visual symptoms in PD may reach up to approximately 80%[3]. Despite the high prevalence rate, visual symptoms are often underreported and undertreated[3]. Visual changes are multi-faceted with the origin being attributable to retinal dysfunction, disturbed eye movement control, or dysfunctional attention networks[4,5]. There is evidence that visual cognitive impairment (difficulties with visual attention and visual processing of information) may be among the earliest of the non-motor symptoms that arise in PD[6].

There are three key eye movements types that may be affected in individuals with PD[7]:

1. Saccadic eye movements: the rapid eye movements that redirect our gaze to localize an object of interest. They are also important in reading words on printed lines of a page.

    – Difficulties can lead to challenges with localizing objects in the environment and reading.

2. Pursuit eye movements: eye movements stabilize the object on our retina and follow it as it moves slowly through space, i.e. tracking.

    – Decreased pursuit eye movements can lead to slowed visual processing.

3. Vergence eye movements: eye movements that serve to move the eyes in different directions (either together, which is convergence, or apart, which is divergence), keeping an image stable on our retina as it moves toward or away from our eyes in depth. This type of eye movement helps us avoid double vision.

    – Such symptoms can result in difficulties adjusting to information in near view, which can cause eyestrain, headaches, and double vision when working on near tasks. This condition is particularly vulnerable to getting worse due to medications used to treat tremors and spasms often seen in PD (i.e., MAO-B inhibitors, dopamine agonists, anticholinergic medication).

Although many individuals with PD may be without symptoms of visual changes, associated signs and symptoms may include double vision, deficits in vision clarity/blurred vision, color vision, blink reflex, pupil reactivity, saccadic and smooth pursuit movements (as described above), as well as more complex functions such as spatial orientation, facial recognition, and visual hallucinations[8,9,10]. Visual testing can aid diagnosis — differentiating PD from other movement disorders with visual symptoms (i.e., progressive supranuclear palsy (PSP)) — and treatment considerations.

While the symptoms of PD can be treated using drug therapy or surgery, these treatments may have side effects impacting eye [motor] movement control, which can complicate management of visual disturbances[11,12]. Visual side effects can vary in their onset, occurring rapidly after beginning medications, after a change in medication, or after a prolonged period of medication use. PD medications can have side effects including pupil dilation, discomfort or pain in the eyes, dry eyes, blurred vision, prolonged response time for eye movements, and worsening of visual hallucinations[8].

It is important to distinguish symptoms due to adverse medication reactions from those due to the disease, and to monitor and treat symptoms as they arise, as visual deficits may significantly impact function and general quality of life. Performing tasks of daily living, such as meal preparation, driving, medication management[13]. The impact of these visual problems on the health-related quality of life of patients with PD is not yet well established. Continued research focused on understanding the experience of visual disturbance in persons with PD has important implications.

OBJECTIVES

1. To identify relationships between age, PD duration, and perceived vision difficulties from the patient's perspective.
2. To understand the patient's perspective about assessment and treatment related to vision function.
3. To understand the impact of vision difficulties on quality of life.

METHODS

- Participants were recruited from prior survey participation conducted by The Parkinson Alliance (PA), announcements at PD support groups, announcements in medical clinics, The PA website, and a DBS-focused affiliate website to The PA (DBS4PD.org).
- There were 1,101 individuals who participated in this survey, including 287 participants with PD who underwent **DBS** and 814 individuals with PD without DBS (**Non-DBS group**; see Table 1 for demographics and clinical features).
- Participants represented 50 states, with California (15%), Texas (10%), Arizona (9%), New Jersey (8%), Florida (8%), New York (8%), Pennsylvania (5%), Colorado (3%), Minnesota (3%), and Michigan (3%) being the top 10 states with the most participants. Geographical distribution was comparable between groups. There were 32 international participants.
- For participants in this survey, approximately 88% completed their survey independently, whereas, 12% of participants required assistance.

Measures:

The questionnaires used in this survey included: The Demographic Questionnaire, an instrument created by the Parkinson Alliance entitled to assess visual symptoms experienced and to what extent participants in the study were bothered by visual symptoms, and additional questions related to vision and quality of life.

The Demographic Questionnaire:

- The self-report questionnaire inquired about basic demographic information (e.g., gender, marital status, education), as well as pertinent clinical information pertaining to vision, vision assessment and treatment, and quality of life.

Parkinson Alliance Vision Symptom Scale (PAVSS):

- The PAVSS is a 44-item, self-report questionnaire with 22 vision-related symptom questions presented in a two-step process: 1. to what extent does one **"experience"** symptoms and 2. to what extent is one **"bothered"** by vision symptoms (see Tables 2 and 3 for specific items).
- For the items related to the "experience" of vision symptoms, the participants respond to a 4-point Likert scale: 0 = No difficulty; 1 = Rare or a little bit of difficulty; 2 = Sometimes or often having difficulty, and 3 = Most or all of the time having difficulty. In each domain, the values were added together to create a total score for "experience of vision symptoms." Higher scores mean greater difficulties with vision. A total score was also calculated by using the sum of all the question items; total scores were only calculated for participants who responded to all items (score range: 0-66).
- For the items related to the "bothered" by vision symptoms, the participants respond to a 3-point Likert scale: 0 = Not at all bothered; 1 = somewhat bothered; 2 = Moderately to extremely bothered. There was an option to select

"Not Applicable." In each domain, the values were added together to create a total score for "experience of vision symptoms." Higher scores mean greater difficulties with vision. A total score was also calculated by using the sum of all of the items within this domain; total scores were only calculated for participants who responded to all items (score range=0-44).

Comparisons based on age and disease duration groups:

- The results will be presented using the entire sample for individuals who completed the survey (N=1,101) and in the context of groups matched on age and disease duration.
  - Age: Age groups were divided into a **Younger PD group** (ages 50-69 years of age) and an **Older PD group** (ages 70+ years).
  - Disease Duration: To better illustrate the impact of disease duration on variables related to vision in individuals with PD, this survey divided disease duration groups into **Early Stage PD (<6 years), Early Advanced Stage PD (6-10 years),** and **Late Advanced Stage PD (11+ years)**.

Factors to consider when int**erpreting the results:**

- This study used a survey-based methodology. Generalizability of the results are limited. Interpretation of the results must keep in mind that responses to the questions in this survey are subjective and portray the "patient's perspective" and awareness about the experience with vision and related information noted in this report. 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.

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's** age was comparable to the **DBS group (average: 71 versus 68 years, respectively).** By contrast, the **DBS group** had a younger average age of PD diagnosis **(52 years)** than the **Non-DBS group (64 years)** and a longer duration of PD (see Table 1). Gender (male greater than female), marital status (the majority being married), race (the majority being White/Caucasian), living with someone, and education (the majority having higher education) were comparable between these two groups.

Table 1. Demographics and Clinical Features of the Sample

	DBS (*n* =377)	**Non-DBS (*n* =1,013)**
Average Age in Years (range)	68 (44-89)	71 (43-98)
Duration of PD in Years (range)*	16 (2-39)	8 (0-34)
Average Age of PD Diagnosis (range)*	52 (30-77)	64 (27-93)
Average Age at Time of DBS in Years (range)	61 (36-84)	n/a
Average Duration since DBS in Years (range)	6 (0-29)	n/a
Target: STN	44%	n/a
GPi	8%	n/a
Not Sure	48%	n/a
Male	59%	55%
Female	41%	45%

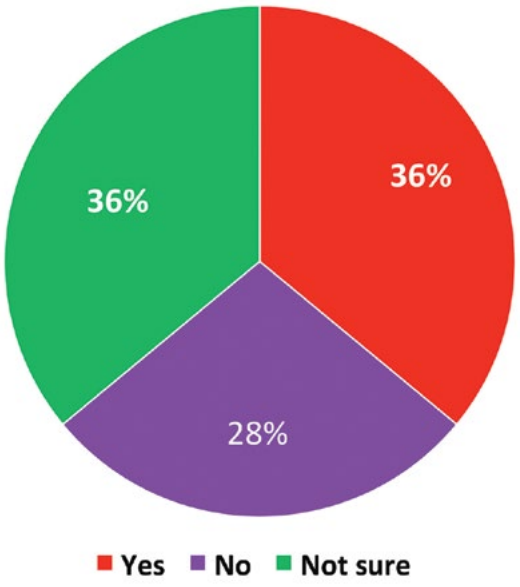
Married	79%	74%
Lives Alone	11%	18%
Race		
Caucasian	94%	94%
Latino/Hispanic	4%	3%
African American	< 1%	<1%
Asian	1%	2%
American Indian	<1%	<1%
Native Hawaiian or Pacific Islander	0%	<1%
Other	n/a	n/a
Education		
<12 years	3%	3%
High School	8%	9%
Some College or Associate's Degree	25%	21%
College	29%	29%
Graduate/Advanced Degree	35%	38%

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

PERCEIVED VISION DIFFICULTIES (whole sample)

- 65% of the participants reported good vision prior to a diagnosis of PD, with 25% reporting poor vision/vision difficulties prior to PD, and 10% being unsure as to whether or not they had poor vision prior to PD.
- 26% reported that others have expressed concerns about their vision.
- 36% perceived that vision has changed secondary to PD (see Figure 1).

Figure 1. Percentage of Participants Reporting Vision Changes due to PD (N=1090):



Parkinson Alliance Vision Symptom Scale (PAVSS):

- Of the 22 symptoms, many were characterized as being experienced **"sometimes"** or **"most of/all of the time"** for a large portion of the study participants (see Figure 2).
  - The top five symptoms/difficulties experienced as **"sometimes"** or **"most of/all of the time"** include: reading difficulty, nighttime vision difficulties, glare sensitivity, visual fatigue, nearsightedness.
- Of the 22 symptoms, at least half of the of the participants reported that 9 of 22 items of vision symptoms/difficulties "**somewhat bothersome**" to "**extremely bothersome**" (see Figure 3).
  - The top five symptoms/difficulties reported as being "**somewhat bothersome**" to "**moderately/extremely bothersome**" include: reading difficulty, glare sensitivity, visual fatigue, nighttime vision, and blurred vision.

Figure 2. Top 10 visual symptoms and difficulties most frequently EXPERIENCED by participants as "sometimes/often" to "all of the time"

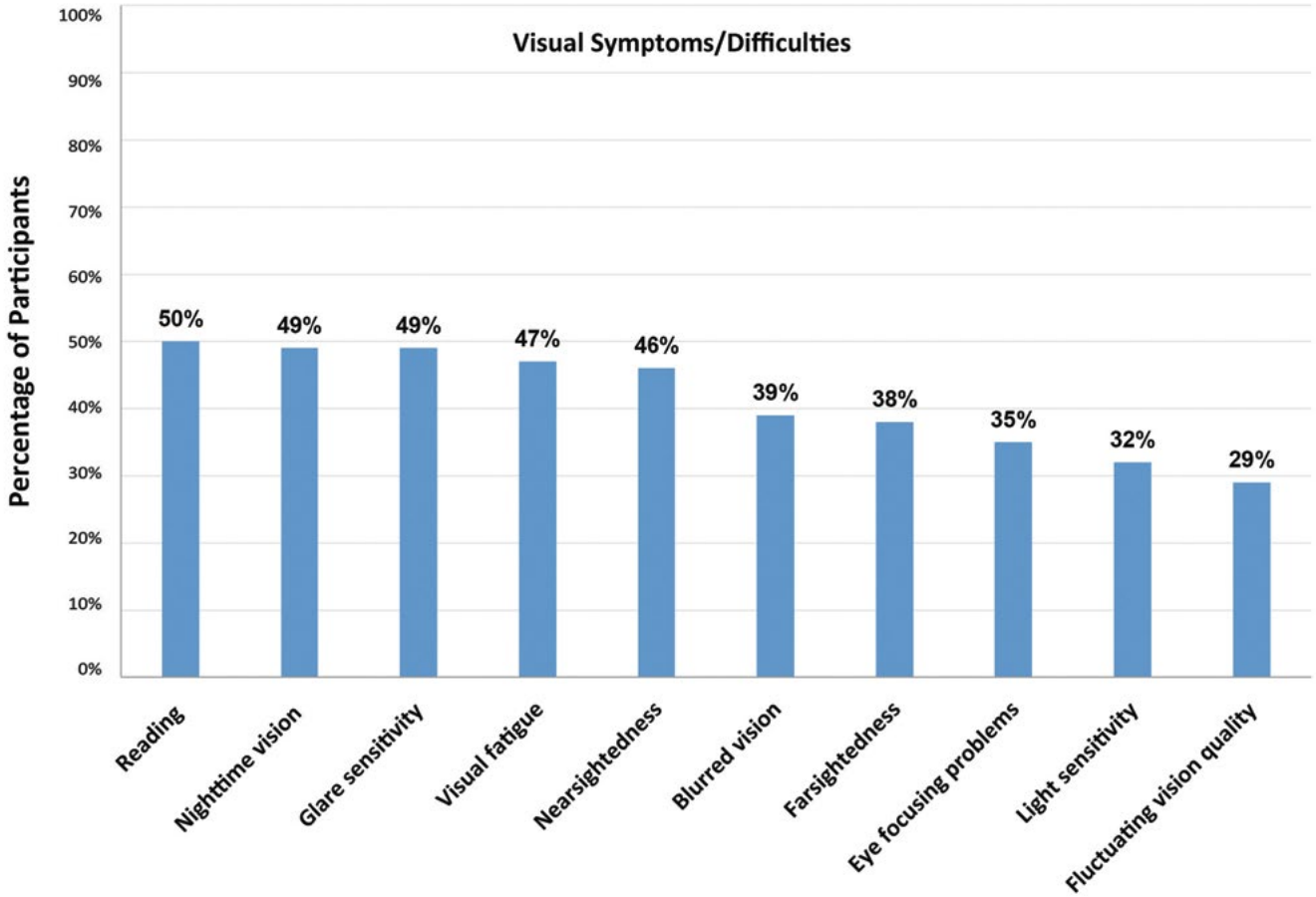
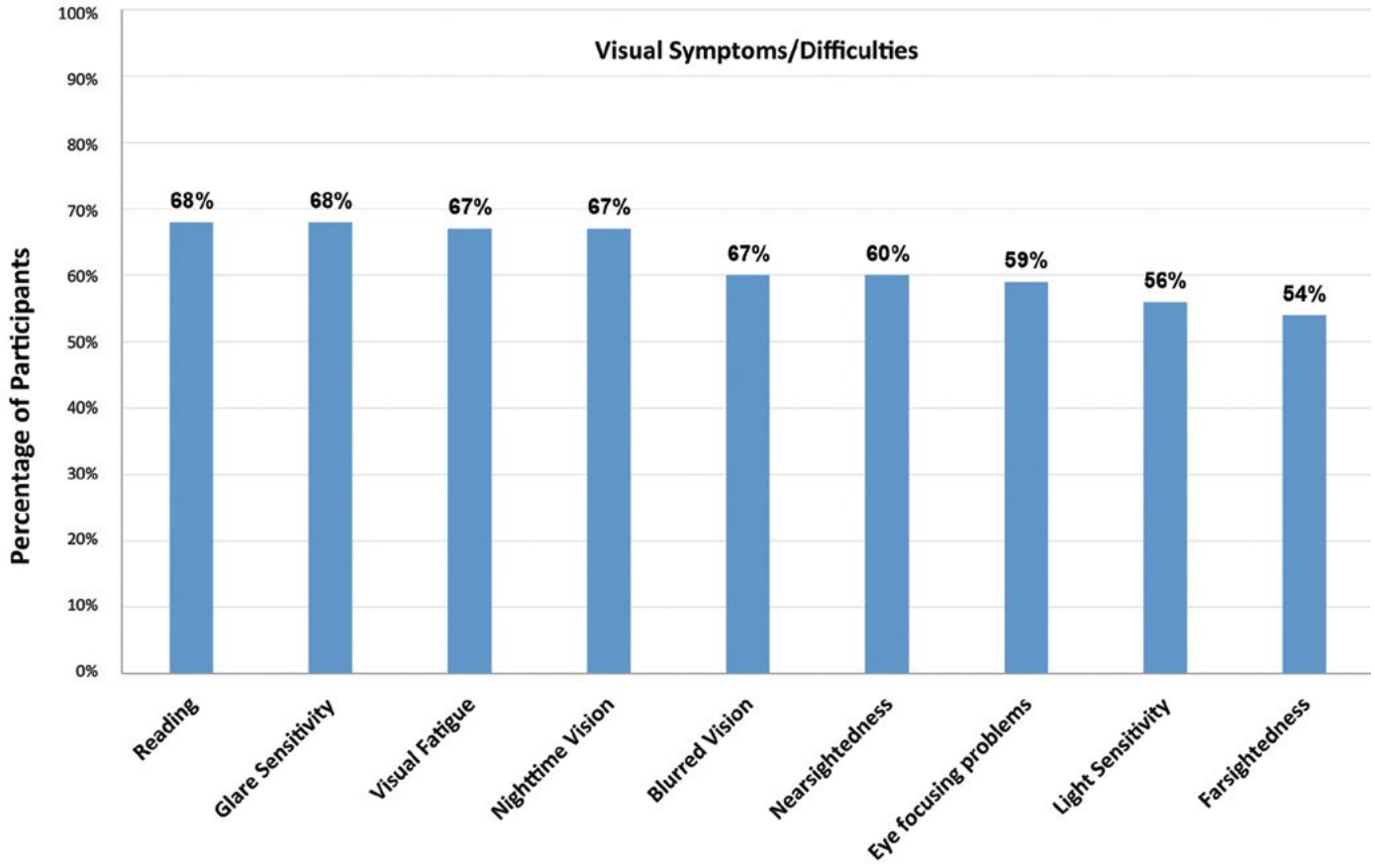


Figure 3. Visual symptoms and difficulties most frequently reported as "somewhat" to "moderately/extremely" BOTHERSOME to participants



Parkinson Alliance Vision Symptom Scale (PAVSS): AGE AND DISEASE DURATION-MATCHED GROUPS

Vision Symptoms/Difficulties EXPERIENCED:

- The experience of changes with vision was highly reported across age and disease duration-matched groups.
- Age and disease duration independently appear to impact visual changes with individuals with PD. Moreover, as age increases and as disease duration increases, vision symptoms/difficulties were reported in greater frequency.
- For most vision symptoms, symptoms were reported in greater frequency with increased age and disease duration-matched groups.
    - **Younger PD Group –** vision symptoms/difficulties were reported with higher frequency as **disease duration increased.**
    - **Older PD Group –** vision symptoms/difficulties were reported with higher frequency as **disease duration increased**).
- For the majority of the symptoms, the **Late Advanced Disease Duration Group (PD Duration 11+ Years)** who were in the in the **Younger** and **Older Age Groups** had the highest frequency of vision symptoms/difficulties for the majority of items.

Vision Symptoms/Difficulties that are BOTHERSOME to participants:

- For those individuals who experience vision symptoms/difficulties, there is a high frequency of participants indicating that changes in vision/difficulties are bothersome, ranging from somewhat bothered to moderately/extremely bothered.

- For many of the items, being bothered by vision symptoms/difficulties was reported in greater frequency with increased age and increased disease duration-matched groups.
  - **Younger PD Group**: Participants reported vision symptoms/difficulties being **bothersome** with higher frequency as disease duration increased.
  - **Older PD Group:** Participants reported vision symptoms/difficulties being **bothersome** with higher frequency as disease duration increased.
- There was a significantly greater number of individuals in the **Late Advanced Disease Duration Group (PD Duration 11+ Years)** reporting that they are bothered by vision disturbance when compared to **Early (Less than 6 years)** and **Early Advanced Disease Duration (6-10 years)** groups.

Table 2. Vision Symptoms EXPERIENCED by Participants: Matched by Age and Disease Duration Cohorts

	Early PD Group (<6 years duration)		Advanced PD Group 6-10 years duration		Advanced PD Group 11+ years duration	
	Younger (50-69) (n =248-279)	Older (70+) (n =205-210)	Younger (50-69) (n =151-156)	Older (70+) (n = 232-240)	Younger (50-69) (n =206-209)	Older (70+) (n =291-301)
Seeing Close Range						
None/little	61%	63%	50%	60%	46%	43%
Somewhat/often	23%	18%	32%	27%	27%	41%
Most or all of the time	16%	19%	18%	13%	27%	17%
Seeing Far Away						
None/little	71%	73%	63%	67%	50%	53%
Somewhat/often	19%	15%	30%	23%	31%	32%
Most or all of the time	10%	12%	7%	10%	19%	15%
See objects in Between						
None/little	84%	83%	82%	60%	71%	60%
Somewhat/often	13%	12%	15%	27%	26%	36%
Most or all of the time	3%	5%	3%	13%	3%	4%
Eye Focus						
None/little	77%	71%	68%	64%	63%	53%
Somewhat/often	19%	20%	27%	27%	30%	33%
Most or all of the time	4%	9%	5%	9%	8%	13%
Reading						
None/little	64%	59%	48%	52%	39%	38%
Somewhat/often	24%	25%	31%	30%	37%	37%
Most or all of the time	12%	16%	21%	18%	24%	35%
Visual Fatigue						
None/little	66%	61%	52%	55%	45%	45%
Somewhat/often	25%	29%	35%	32%	43%	33%
Most or all of the time	10%	10%	13%	14%	12%	22%
Visual Scanning						
None/little	91%	82%	84%	81%	81%	73%
Somewhat/often	7%	12%	8%	12%	16%	18%
Most or all of the time	2%	6%	8%	8%	3%	9%

Nighttime Vision						
None/little	56%	62%	45%	49%	48%	49%
Somewhat/often	27%	25%	34%	34%	32%	30%
Most or all of the time	18%	13%	21%	17%	21%	21%
Glare Sensitivity						
None/little	58%	59%	47%	53%	49%	43%
Somewhat/often	27%	27%	31%	27%	30%	32%
Most or all of the time	15%	14%	22%	20%	21%	25%
Objects Different Shape/Size						
None/little	92%	89%	93%	83%	86%	80%
Somewhat/often	7%	7%	4%	22%	12%	15%
Most or all of the time	1%	4%	3%	5%	2%	5%
Depth Perception						
None/little	79%	76%	74%	67%	67%	61%
Somewhat/often	15%	14%	15%	22%	19%	25%
Most or all of the time	6%	10%	11%	11%	14%	14%
Vision Field Loss						
None/little	89%	86%	87%	85%	90%	81%
Somewhat/often	11%	11%	8%	11%	7%	13%
Most or all of the time	0%	3%	5%	4%	3%	6%
Blurred Vision						
None/little	63%	70%	66%	64%	60%	50%
Somewhat/often	31%	24%	26%	24%	32%	36%
Most or all of the time	6%	6%	8%	12%	8%	14%
Double Vision						
None/little	82%	81%	76%	70%	73%	63%
Somewhat/often	13%	13%	16%	20%	19%	23%
Most or all of the time	5%	6%	8%	10%	8%	14%
Changes in Brightness						
None/little	85%	83%	82%	77%	81%	69%
Somewhat/often	11%	14%	13%	17%	16%	23%
Most or all of the time	4%	3%	5%	7%	3%	8%
Light Sensitivity						
None/little	72%	75%	71%	69%	68%	59%
Somewhat/often	17%	20%	20%	21%	25%	28%
Most or all of the time	11%	5%	9%	10%	7%	13%
Color Vision						
None/little	95%	95%	97%	94%	93%	94%
Somewhat/often	4%	4%	2%	5%	6%	4%
Most or all of the time	1%	1%	1%	1%	1%	2%
Visual Hallucinations						
None/little	87%	91%	87%	87%	85%	73%
Somewhat/often	11%	5%	10%	10%	13%	20%
Most or all of the time	2%	4%	3%	3%	2%	7%
Fluctuation in Vision Quality						

None/little	73%	18%	73%	75%	65%	61%
Somewhat/often	22%	18%	22%	20%	28%	32%
Most or all of the time	5%	2%	5%	5%	7%	7%
Eyelid Apraxia						
None/little	92%	89%	87%	89%	70%	67%
Somewhat/often	7%	9%	12%	9%	23%	20%
Most or all of the time	1%	2%	2%	3%	6%	13%
Ptosis						
None/little	90%	87%	87%	83%	73%	68%
Somewhat/often	6%	12%	10%	12%	22%	24%
Most or all of the time	4%	1%	3%	5%	5%	8%
Belpharospasm						
None/little	94%	97%	90%	91%	85%	84%
Somewhat/often	5%	2%	8%	6%	12%	12%
Most or all of the time	1%	1%	2%	3%	3%	4%

Table 3. Percentage of Participants BOTHERED by Vision Symptoms: Matched by Age and Disease Duration Cohorts

* Percentages do not equate to 100%, as individuals who reported "not applicable" were not shown in the table below. The percentage below includes those who experience the symptom and to what extent they are bothered by the symptom.

	Early PD Group (<6 years duration)		Advanced PD Group 6-10 years duration		Advanced PD Group 11+ years duration	
	Younger (50-69) (n =248-279)	Older (70+) (n =205-210)	Younger (50-69) (n =151-156)	Older (70+) (n = 232-240)	Younger (50-69) (n =206-209)	Older (70+) (n =291-301)
Seeing Close Range						
Not at all bothered	41%	51%	31%	41%	26%	32%
Somewhat bothered	41%	30%	42%	35%	41%	37%
Moderate to extremely	16%	15%	24%	22%	32%	29%
Seeing Far Away						
Not at all bothered	47%	52%	47%	46%	35%	35%
Somewhat bothered	38%	32%	37%	38%	41%	41%
Moderate to extremely	12%	11%	11%	15%	22%	22%
See objects in Between						
Not at all bothered	65%	69%	65%	59%	59%	47%
Somewhat bothered	24%	23%	22%	27%	23%	35%
Moderate to extremely	5%	4%	7%	10%	12%	13%
Eye Focus						
Not at all bothered	39%	45%	41%	41%	33%	26%
Somewhat bothered	43%	40%	38%	40%	41%	39%
Moderate to extremely	14%	11%	18%	16%	24%	28%

Reading						
Not at all bothered	40%	40%	29%	29%	18%	17%
Somewhat bothered	35%	29%	36%	36%	41%	36%
Moderate to extremely	22%	26%	31%	30%	36%	41%
Visual Fatigue						
Not at all bothered	45%	32%	30%	26%	27%	22%
Somewhat bothered	31%	41%	36%	39%	41%	36%
Moderate to extremely	23%	24%	31%	30%	30%	26%
Visual Scanning						
Not at all bothered	70%%	64%	62%	59%	64%	48%
Somewhat bothered	22%	24%	23%	28%	18%	33%
Moderate to extremely	4%	7%	10%	7%	12%	14%
Nighttime Vision						
Not at all bothered	30%	30%	29%	26%	23%	26%
Somewhat bothered	39%	39%	38%	38%	44%	37%
Moderate to extremely	24%	25%	27%	32%	27%	33%
Glare Sensitivity						
Not at all bothered	34%	24%	29%	29%	25%	21%
Somewhat bothered	42%	43%	35%	39%	44%	42%
Moderate to extremely	20%	26%	29%	27%	26%	32%
Objects Different Shape/Size						
Not at all bothered	78%	77%	77%	71%	68%	60%
Somewhat bothered	12%	13%	12%	20%	19%	23%
Moderate to extremely	2%	4%	2%	4%	5%	10%
Depth Perception						
Not at all bothered	58%	53%	47%	48%	47%	35%
Somewhat bothered	25%	29%	31%	30%	28%	38%
Moderate to extremely	11%	14%	16%	17%	20%	22%
Vision Field Loss						
Not at all bothered	65%	64%	66%	64%	67%	61%
Somewhat bothered	19%	23%	18%	22%	20%	25%
Moderate to extremely	6%	4%	7%	6%	7%	8%
Blurred Vision						
None/little	40%	42%	39%	37%	34%	25%
Somewhat/often	35%	41%	35%	43%	39%	46%
Most or all of the time	18%	11%	20%	17%	25%	24%
Double Vision						
Not at all bothered	65%	61%	58%	50%	53%	41%
Somewhat bothered	12%	19%	22%	25%	20%	30%
Moderate to extremely	11%	12%	13%	18%	21%	23%
Changes in Brightness						
Not at all bothered	54%	47%	60%	50%	49%	41%
Somewhat bothered	30%	39%	24%	33%	33%	38%
Moderate to extremely	10%	7%	8%	13%	12%	16%

Light Sensitivity						
Not at all bothered	43%	39%	44%	44%	38%	31%
Somewhat bothered	34%	44%	34%	36%	42%	42%
Moderate to extremely	17%	10%	15%	17%	17%	21%
Color Vision						
Not at all bothered	80%	78%	80%	77%	76%	67%
Somewhat bothered	9%	10%	8%	13%	12%	19%
Moderate to extremely	10%	13%	3%	2%	3%	40%
Visual Hallucinations						
Not at all bothered	64%	68%	80%	66%	58%	53%
Somewhat bothered	16%	13%	8%	18%	24%	26%
Moderate to extremely	6%	7%	3%	6%	8%	12%
Fluctuation in Vision Quality						
Not at all bothered	45%	41%	42%	38%	35%	31%
Somewhat bothered	33%	39%	41%	39%	44%	43%
Moderate to extremely	16%	13%	11%	15%	19%	21%
Eyelid Apraxia						
Not at all bothered	66%	73%	64%	64%	47%	43%
Somewhat bothered	17%	12%	19%	21%	27%	72%
Moderate to extremely	3%	6%	9%	5%	17%	91%
Ptosis						
Not at all bothered	65%	69%	60%	65%	55%	45%
Somewhat bothered	18%	15%	23%	19%	26%	30%
Moderate to extremely	4%	6%	8%	5%	10%	16%
Belpharospasm						
Not at all bothered	67%	79%	71%	74%	63%	60%
Somewhat bothered	16%	9%	11%	12%	20%	19%
Moderate to extremely	3%	2%	7%	1%	9%	10%

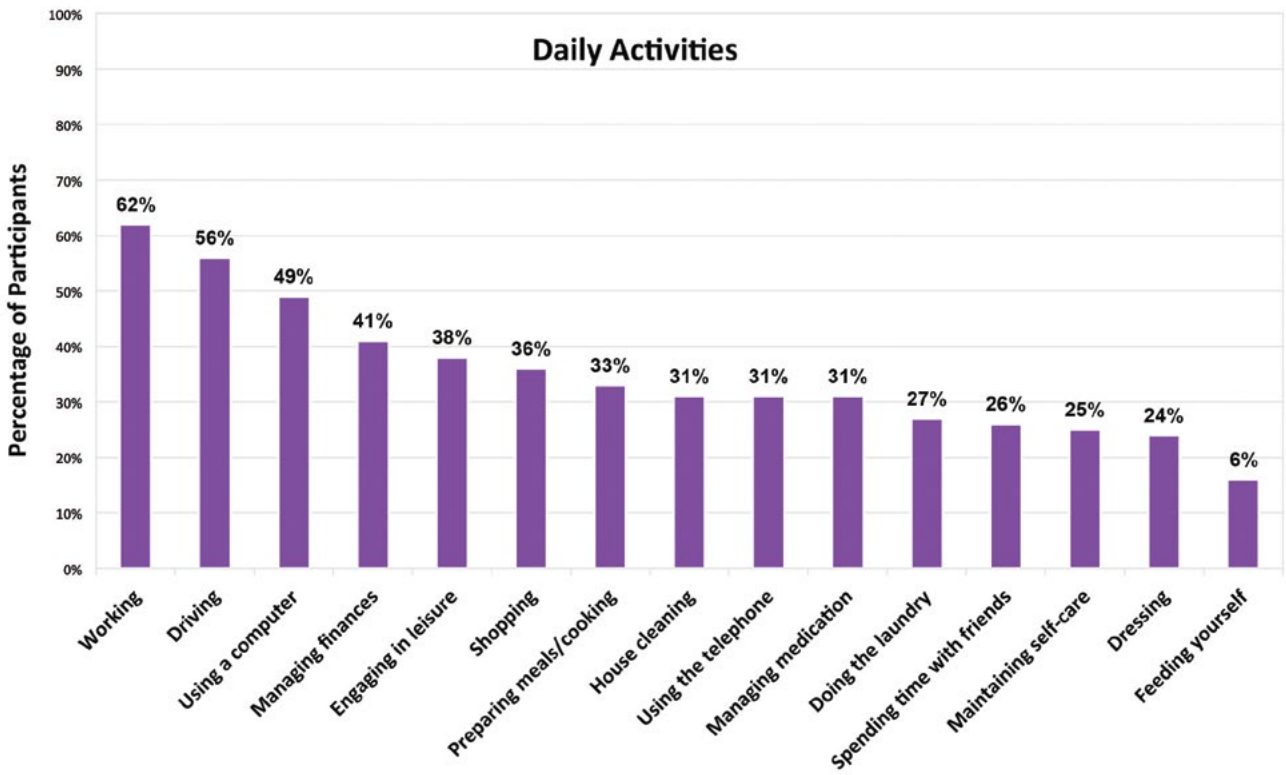
IMPACT OF VISION ON DAY-TO-DAY FUNCTIONS:

69% of the participants reported that vision difficulties adversely impact their day-to-day activities.

- 39% - a little bit
- 17% - moderately
- 11% - quite a bit
- 3% - extremely

- 35% of the participants reported requiring assistance in completing activities at home because of visual disturbance.
  - 24% requiring minimal assistance
  - 9% requiring moderate assistance
  - 2% reporting major assistance
  - <1% reporting that they are unable to perform activities due to visual disturbance
- Vision disturbance adversely impacted engagement in daily activities (Figure 4).
- The top five daily activities with an adverse impact secondary to vision difficulties included: working, driving, using a computer, managing finances, and engaging in leisure activities (see Figure 4).

Figure 4. Percentage of participants reporting that vision difficulty impacts engagement in daily activities.



Falling and Vision:

- There was a significant relationship between vision dysfunction and falling.
- Many participants reported that visual dysfunction impacted falling:
  - 28% view vison dysfunction as having "a little bit" of an impact on falling
  - 9% "moderate" impact on falling
  - 4% "quite a bit" of an impact on falling
  - 5% view vision disturbance as having an "extreme" impact on falling

Quality of Life (QOL; see Figures 5 and 6):

- 74% rated QOL as "good" to "excellent"
- 21% rated QOL as "excellent"
- 73% reported that vision difficulties adversely impacted QOL
  - 42% reporting "a little bit" of an impact on QOL
  - 31% reported moderately to extremely impacting QOL

Figure 5

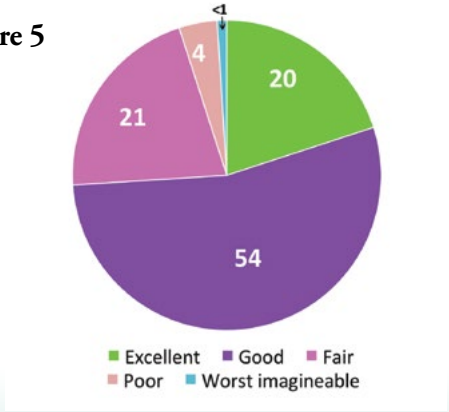
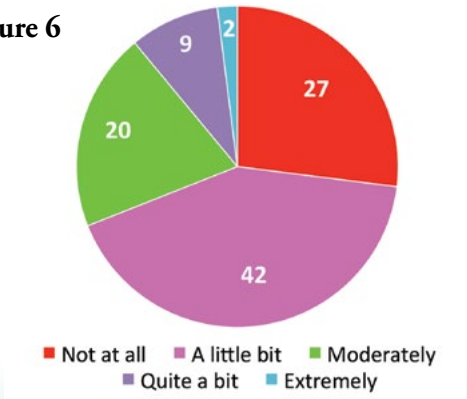


Figure 6



EVALUATION AND TREATMENT FOR VISION DIFFICULTIES:

- 88% of the participants reported that they have had their vision evaluated.
- For the participants in this study, vision assessments have been conducted by the following clinicians:
  - Ophthalmologist (51%)
  - Optometrist (49%)
  - Neurologist (13%)
  - Neuro-ophthalmologist (6%)
  - Occupational Therapist (3%)
  - Neuro-optometrist (2%)
- Treatments for vision symptoms/difficulties have included:
  - Glasses/contacts (82%)
  - LASIK surgery (10%)
  - Treatment for Glaucoma (8%)
    - Glaucoma is a disease that damages your eye's optic nerve. It usually happens when fluid builds up in the front part of the eye. That extra fluid increases the pressure in the eye, damaging the optic nerve.
  - Treatment for Cataracts (35%)
    - Cataract is when the lens of an eye becomes cloudy.
  - Treatment for Macular Degeneration (2%)
    - Macular Degeneration is the deterioration of the central portion of the retina.
  - Vision Therapy (4%)

SUMMARY & DISCUSSION

Vision changes can be a symptom in PD and carry a reported prevalence of approximately 80%[3]. Despite the high prevalence rate, visual symptoms are often underreported and undertreated[3]. The impact of these problems on the health-related quality of life of patients with PD is not yet well established. In this report, we shed light on these problems and their relationships to QOL.

General Take Home Points:

- Individuals with PD experience a broad scope of visual symptoms. Getting a better understanding about the experience of visual disturbance from the patient's perspective may guide assessment strategies and treatment.
- Across the range of reported symptom frequency ("infrequent" to "all the time"), a large number of participants reported that the vision symptoms were bothersome and interfere with day-to-day activities.
- The symptoms and difficulties most frequently reported by individuals with PD include: reading difficulty, nighttime vision difficulties, glare sensitivity, visual fatigue, and nearsightedness, though many other visual symptoms were reported by the participants in this survey.
- Vision disturbance adversely impacted engagement in daily activities, and vision dysfunction can result in higher risk for falls.

OBJECTIVE 1: To identify relationships between age, PD duration, and severity of perceived vision difficulties from the patient's perspective.

- There is significant risk for vision difficulties as age and disease duration increase.
- Independent of age, disease duration had a strong relationship with the experience of vision difficulties. Moreover, the **Late Advanced Disease Duration Group (PD Duration 11+ YEARS)** who were in the **Younger** and **Older Age Groups** had the highest frequency of vision symptoms/difficulties for the majority of items. Disease duration more so than age appears to be a better predictor for increased vision difficulties.
    - The **Advanced Disease Duration group (11+ years)** for **both Younger and Older participants** reported symptoms in greater frequency of vision symptoms as compared to the **Early Disease Duration** and **Advanced 6-10 Years Disease Duration groups**, suggesting that disease duration increases the risk for vision difficulties for individuals with PD.
- Of the 22 symptoms, many were characterized as being experienced **"sometimes"** or **"most of/all of the time"** for a large portion of the study participants.
    - The top five symptoms/difficulties experienced as **"sometimes"** or **"most of/all of the time"** include: reading difficulty, nighttime vision difficulties, glare sensitivity, visual fatigue, nearsightedness
- Of the 22 symptoms, at least half of the of the participants reported that 9 of 22 items of vision symptoms/difficulties were "**somewhat bothersome**" to "**moderately/extremely bothersome.**"
    - The top five symptoms/difficulties reported as being "**somewhat bothersome**" to "**moderately/extremely bothersome**" include: reading difficulty, glare sensitivity, visual fatigue, nighttime vision, and blurred vision.

OBJECTIVE 2: To understand the patient's perspective about assessment and treatment related to vision function.

- Assessments were predominately conducted by Ophthalmologists (51%) and Optometrists (49%).
- A large portion of the study participants reported use of glasses, with much fewer reporting use of surgical or medication intervention. Very few have reported participating in non-medication vision therapy.

OBJECTIVE 3: To understand the impact of vision on quality of life.

- 74% of the participants reported good to excellent general quality of life.
- Despite a high percentage of participants indicating good to excellent quality of life, 73% reported that vision difficulties adversely impacted QOL.
    - 42% of the participants reported that vision difficulties adversely effect QOL "a little bit."
    - 31% characterized the adverse impact of vision on QOL as "moderately" to "extremely."

GENERAL THOUGHTS AND RECOMMENDATIONS:

- The visual system is very sensitive and highly complex with significant implications for functional difficulties in day-to-day activities when disturbances occur. Assessment of visual dysfunction and recommendations for treatment (including medical and rehabilitation intervention) is recommended for individuals with PD.
    - Meeting with a vision specialist (i.e., Neuro-optometrist; Neuro-ophthalmologist) to assess causality of vision difficulties and provide recommendation for treatment may be of help to individuals with vision impairment or loss.
    - Some visual disturbance may benefit from rehabilitation therapy to assist with both restoration of and compensatory strategies for visual difficulties.

    - A referral to an occupational therapist who specializes in vision therapy may be constructive.
    - There was a significant relationship between falls and vision dysfunction. Rehabilitation intervention may provide some benefit in treating these symptoms.
- Discussing the possibility of vision changes due to medications with your Neurologist is also important. For example, use of dopamine agonists may exacerbate visual hallucinations in PD; some MAO-B inhibitors and multiple dopamine agonists may precipitate blurring of vision and loss of visual acuity; anticholinergic medication may create light sensitivity, dry eyes, decreased accommodation, and blurred vision; L-Dopa/Carbidopa may cause blepharospasm, eyelid ptosis, and may affect saccades (rapid eye movements), Amantadine may result in reduced accommodation or hallucinations.
- Given the high prevalence of vision difficulties and the impact such difficulties have on feelings of isolation, emotional disturbance, and reduced quality of life, cognitive-behavioral therapy (psychotherapy) may also be a helpful treatment to assist individuals cope with life changes resulting from vision difficulties[14].
- Continued research on vision function across age and disease duration groups and the impact on well-being for individuals with PD is needed.
- Patient reported outcomes is important. Moreover, measurement from the patient's perspective is important and needed because 1. Clinicians and patient perspectives may differ, 2. These measures often gauge the impact of a disease or condition in a daily living setting, 3. This information can guide management strategies, and 4. Patient reported experiences can validate and comfort individuals with similar experiences.

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