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in the Parkinson's Community



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

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INTRODUCTION

In recent decades, neuroscientists have become increasingly aware that cognitive dysfunction is an expected change for many individuals with Parkinson's disease (PD). Cognitive dysfunction can be among the most debilitating PD symptoms because of its potential to adversely impact engagement in daily activities. PD-related cognitive difficulties are a concerning change for individuals with PD, family members and care providers, and clinicians. For many, however, the concepts related to and classification of cognitive changes remain unclear or can be misunderstood.

Cognition Defined:

Cognition can be defined as mental skills that help us function day-to-day and include, but are not limited to, attention and concentration, learning, storing and retrieving memories, expressing and understanding language, making sense of visual information, and “executive functions” such as managing complex information, organizing, planning, understanding abstract concepts, reasoning, anticipating consequences, strategizing to reach goals, self-monitoring, and evaluating progress.

Before discussing the cognitive difficulties commonly seen in people with PD, it is important to understand how “normal aging” is also associated with cognitive decline. Across all individuals, cognitive strengths, weakness and difficulties are diverse in the “normal” aging process, but certain cognitive changes are commonplace: changes in processing speed and certain memory, language, visuospatial, and executive function abilities¹. When differentiating normal aging from cognitive impairment that is classified as “abnormal,” normal age-related cognitive changes are small and, should not result in impairment in function in general. More complex and higher level functional activities, such as driving, may be compromised, however, making it important to detect safety issues early¹.

A predominant pattern of cognitive dysfunction in PD involves slowed processing speed and difficulties with attention, memory, and visuospatial functions². That said, the experience of cognitive impairment varies for individuals with PD. Marras and colleagues highlighted that cognitive difficulty in PD exists on a continuum of severity, and is typically divided into two categories, mild cognitive impairment (MCI) and PD-Dementia. MCI refers to cognitive decline that is generally insufficient to impede daily functions (i.e., at home, in the community, and/or at work), though the cognitive changes can cause significant difficulties. For example, even when cognitive difficulties are classified as MCI, slowed processing speed and/or executive dysfunction can result in the inability to perform one's job responsibilities. Such difficulties can be concerning to and perceived as significantly hindering for individuals who are aware of their difficulties/changes in cognition. MCI is an intermediate level of severity between the expected cognitive declines of normal aging and the more serious decline of dementia. It can involve problems with memory, language, attention and concentration, multi-tasking, and judgment that are greater than normal age-related changes. Importantly, MCI for individuals with PD does not necessarily progress to PD Dementia. PD-Dementia is diagnosed when cognitive deficits (i.e., memory and other cognitive functions) are severe enough to impair engagement in and completion of activities of daily living (i.e., managing schedules, preparing food/eating, engaging in house chores, managing medications, driving, etc.). It is important to distinguish between interference in activities of daily living due to motor disturbance versus interference directly influenced by cognitive difficulties, with the latter required for a diagnosis of dementia.

Causes of Cognitive Difficulties:

Changes in brain chemicals (neurotransmitters), such as dopamine – the depletion of which is a cause of motor symptoms of PD, can also lead to changes in thinking skills. Other neurotransmitters, such as acetylcholine and norepinephrine, are also thought to influence cognitive changes for individuals with PD. Many other factors also impact cognition, however. For example, medication effects³, fatigue and sleep disturbance^{4,5}, emotional disturbance (depression and/or anxiety^{6,7}), pain⁸, and malnutrition⁹ can adversely impact cognitive processing. In fact, when these factors are addressed (e.g., resulting in

improved sleep, reduced depression and anxiety, and optimized medication, nutrition, or pain management), cognitive functions can improve.

Treatment of Cognitive Difficulties:

Medications are commonly prescribed to address neurotransmitter deficits in PD that are also associated with cognitive functioning. Treatment effects have been modest, but research has found some benefit with rivastigmine (Exelon), a medication approved by the US Food and Drug Administration (FDA) for dementia in PD. Doctors may also prescribe other medications indicated for cognitive difficulties, such as donepezil (Aricept) and galantamine (Razadyne). In addition, stimulants are sometimes prescribed for individuals who experience fatigue, daytime sleepiness, and attention difficulties.

Whereas benefits of non-pharmacological therapies have been systematically examined in Alzheimer's disease and related conditions resulting in major cognitive impairment, the utility of cognitive rehabilitation or training programs in the PD population is less clear¹⁰. It is important to differentiate cognitive training from cognitive rehabilitation. Cognitive training involves the repetitive practice of specific thinking tasks and has not been shown to be helpful for individuals with significant cognitive changes such as mild dementia¹¹. By contrast, benefits have been demonstrated in preliminary studies of cognitive rehabilitation, a customized behavioral approach where an individual learns specific strategies to target and implement personally relevant goals that reduce functional impairments and increase engagement in daily activities of living^{11,12}. The two types of cognitive rehabilitation strategies involve restorative and compensatory techniques¹³.

Restorative techniques target cognitive functions that will return individuals to a functional level that is close to their baseline – the state prior to the functional decline. Compensatory techniques are designed to offset the impact of cognitive difficulties, e.g., use of strategies to organize information so as to improve recall, learning and self-management.

Research on individuals with PD has primarily focused on cognitive training, rather than cognitive rehabilitation. Several studies demonstrate improvements in various cognitive domains, such as information processing speed, visuospatial and visuoconstructive abilities, memory, and executive functions^{14,15}. One study showed that cognitive training enhanced reaction time and accuracy on task performance¹⁶. However, it is important to note that research studies thus far have not demonstrated efficacy of cognitive training due to their small sample sizes and lack of a control group or long-term follow-up.

In summary, neuroscientists and clinicians specializing in PD are learning about the various manifestations, causes, and implications of cognitive impairment. That said, treatments for cognitive impairment in PD and scientific evidence for the benefits of treatment are in their infancy. Additionally, what is clearly missing is an appreciation of and awareness about the patient's perspective of his or her cognitive difficulties and the perceived impact these challenges have on day-to-day life. Despite research showing that personal insight into or appreciation of one's cognitive deficits is a challenge in self-report¹⁷, understanding the patient's perspective about his or her personal experience of cognitive deficits in and of itself has important implications.

OBJECTIVES

- To understand the patient's perspective about changes in cognition using the measurement of Every Day Cognition (E-Cog).
- To understand how current cognitive difficulties can impact daily life experiences.
- To understand the extent people with PD perceive themselves as
 1. having undergone assessment of cognitive functioning, and
 2. having received treatment for cognitive difficulties.

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, The PA website, or a DBS-focused affiliate website to The PA (DBS4PD.org).
- There were 1,548 individuals who participated in this survey, including 399 participants with PD who underwent **DBS** and 1,149 individuals with PD without DBS (**Non-DBS group**; see Table 1 for demographics and clinical features).
- For the **DBS group** and **Non-DBS group**, approximately 85% completed their survey independently, whereas, 15% of participants required assistance.
- Participants represented 50 states, with California (14%), Florida (10%), Arizona (10%), Texas (9%), New Jersey (9%), New York (8%), Colorado (4%), Pennsylvania (4%), Virginia (3%), and Michigan (2%) being the top 10 states with the most participants. Geographical distribution was comparable between groups. There were 60 international participants.

Measures:

The Demographic Questionnaire, Everyday Cognition (E-Cog), Questions Related to Current Cognitive Functioning, Lawton Instrumental Activities of Daily Living Scale:

The Demographic Questionnaire:

- The self-report questionnaire inquired about basic demographic information (e.g., gender, marital status, education) as well as pertinent clinical information (e.g., engagement in assessment and treatment for cognitive difficulties).

Everyday Cognition (E-Cog¹⁹):

- The self-report questionnaire has 12 items related to cognition in 6 domains: Everyday Memory, Everyday Language, Everyday Visuospatial Abilities, Everyday Planning, Everyday Organization, and Everyday Divided Attention.
- For each item, participants compare their current level of every-day functioning with how he or she functioned several years earlier.
- Ratings are made on a 4-point scale: 1. better or no change compared with several years earlier, 2. questionable/occasionally worse, 3. consistently a little worse, and 4. consistently much worse.

Current Cognitive Functioning (assessment tool developed by The Parkinson Alliance):

- The self-report questionnaire has two sections. The first section is comprised of one question pertaining to one's current level of severity in cognitive functions ranging from "no difficulties" to "severe" difficulties. The second section is comprised of several questions pertaining to perceived CURRENT cognitive difficulties within the following six domains: Confusion, Attention and Concentration, Speed of Information Processing, Initiation, Executive Functions (management of more complex skills, planning, organizing, difficulties engaging in two tasks simultaneously – i.e., multi-tasking), Memory, Language Skills (expression and understanding), and Spatial Abilities.
 - Current cognitive difficulties were rated on a 5-point scale ranging from "not at all" to "severe."

Impact of Cognition on Everyday Life Scale (assessment tool developed by The Parkinson Alliance):

- This self-report questionnaire has 8 questions to investigate how cognitive changes impact everyday life. Questions involved “day-to-day functions,” “relationships,” “social engagement,” “engagement in hobbies/leisure activities,” “work,” and overall “quality of life.”
- Each item was rated on a 5-point scale ranging from “not at all” to “extremely/completely” with the option of indicating “not applicable” on select items.

Instrumental Activities of Daily Living Scale¹⁹:

- This self-report questionnaire has 8 items addressing the following functional skills: Ability to use Telephone, Shopping, Food Preparation, Housekeeping, Laundry, Mode of Transportation, Responsibility for Own Medications, and Ability to Handle Finances.
- Items permit the participant to identify the best descriptor of his or her capability within each domain, ranging from independent to completely dependent on another person’s assistance.

Comparisons based on age and disease duration groups:

- The results will be presented using the entire sample (N=1,548) and 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: In previous research pertaining to individuals with PD, the average time from symptom onset to development of motor complications was 6 years^{20,21}. 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. To better illustrate the impact of disease duration on exercise 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)**.

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. Also, individuals with more severe cognitive impairment - to such a degree that they could not participate in this study - are not represented in this data analysis. Moreover, since this is a self-report questionnaire, the respondents of this survey likely underrepresent those who have severe cognitive impairment. Furthermore, research has found that some individuals with PD (as cognition becomes more severely impaired) may have reduced insight/awareness into or appreciation of his or her difficulties¹⁷, a factor warranting consideration when interpreting self-report questionnaires. As such, subjective report in this survey serves to highlight the “patient’s perspective” of his or her experience with cognitive functions.

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 significantly older than the **DBS group (average: 71 versus 67 years, respectively)**. By contrast, the **DBS group** had a younger average age of PD diagnosis (**52 years**) than the **Non-DBS group (63 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), and education (the majority having higher education) were comparable between groups.

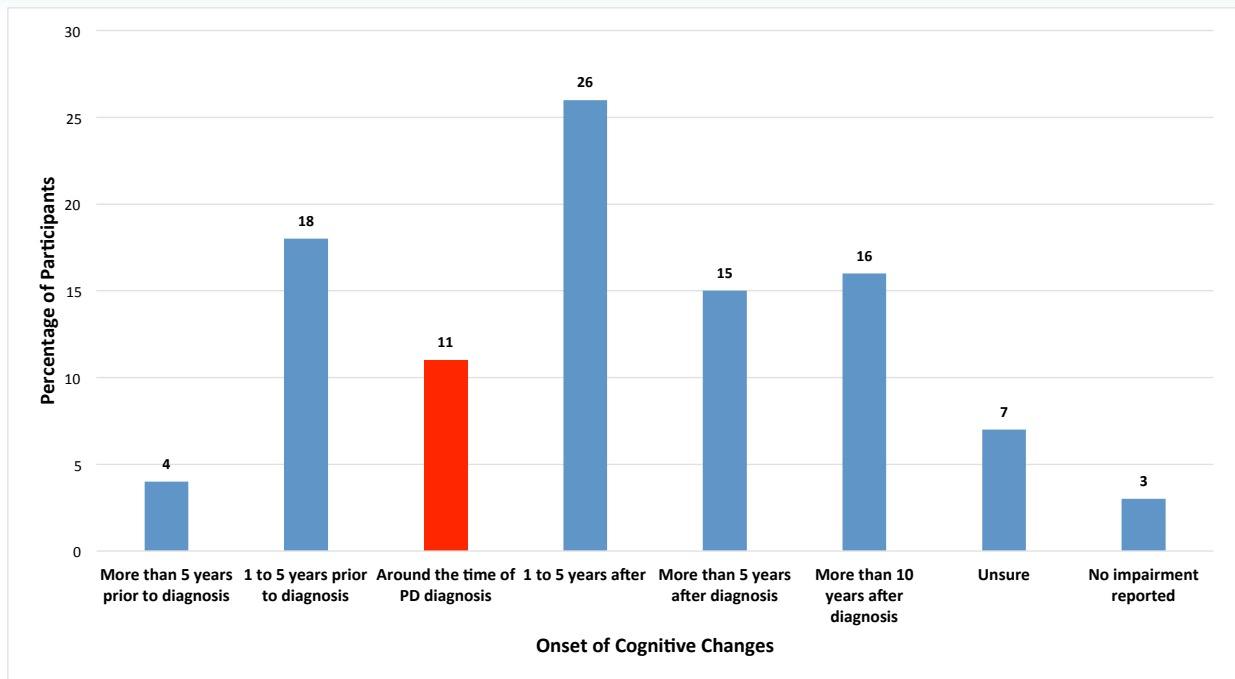
Table 1. Demographics and Clinical Features of the Sample

	DBS (n =399)	Non-DBS (n =1,149)
Average Age in Years (range)*	67 (45-88)	71 (32-104)
Duration of PD in Years (range)*	15 (1-37)	7 (0-35)
Average Age of PD Diagnosis (range)*	52 (30-75)	63 (27-89)
Average Age at Time of DBS in Years (range)	61 (36-82)	n/a
Average Duration since DBS in Years (range)	6 (0-24)	n/a
Target: STN	53%	n/a
GPI	8%	n/a
Not Sure	39%	n/a
Male	56%	53%
Female	44%	47%
Married	78%	77%
Lives Alone	13%	15%
Race		
Caucasian	93%	92%
Latino/Hispanic	3%	3%
African American	<1%	<1%
Asian	1%	2%
American Indian	<1%	<1%
Native Hawaiian or Pacific Islander	<1%	1%
Other	<1%	<1%
Education		
<12 years	4%	3%
High School	6%	9%
Some College or Associate's Degree	27%	21%
College	28%	30%
Graduate/Advanced Degree	35%	37%
* Clinically significant difference between groups n/a = not applicable		

PERCEIVED COGNITIVE CHANGES OVER TIME: PERCEPTION OF THE PARTICIPANT:

- At the time of this survey, out of 953 individuals who responded to the question, a considerable number of participants experienced cognitive changes early in their disease course, even prior to their PD diagnosis (see Figure 1).
 - 22% experienced cognitive difficulties before PD diagnosis
 - 11% experienced cognitive difficulties around the time of PD diagnosis
 - 57% experienced cognitive difficulties following PD diagnosis and as the PD progressed
 - 7% were not sure when cognitive difficulties began
 - 3% have not experienced cognitive difficulties

Figure 1. Onset of cognitive difficulties (N=953):



- For both **Younger and Older PD Groups**, a larger number of individuals within the Early PD Group (disease duration 0 to 5 years) and Early Advanced PD Group (disease duration (6-10 years) reported onset of cognitive difficulties prior to PD diagnosis when compared to the Late Advanced PD Group (disease duration 11+ years).
 - Younger PD Group (ages 50-59) and Early PD Group (Duration 0 to 5 years); n=150:
 - 33% experienced cognitive changes before PD diagnosis
 - 24% experienced cognitive changes around the time of PD diagnosis
 - 36% experienced cognitive changes following PD diagnosis
 - 9% were not sure/did not know
 - Younger PD Group (ages 50-59) and Early Advanced PD Group (Duration 6-10 years); n=131:
 - 21% recall having experienced cognitive changes before PD diagnosis
 - 34% experienced cognitive changes greater than 5 years after PD diagnosis
 - Younger PD Group (ages 50-59) and Late Advanced PD Group (Duration 11+ years); n=193:
 - 11% recall having experienced cognitive changes before PD diagnosis
 - 41% experienced cognitive changes greater than 5 years after PD diagnosis
 - Older PD Group (ages 70+) and Early PD Group (Duration 0 to 5 years); n=178:
 - 38% recall having experienced cognitive changes before PD diagnosis
 - 34% experienced cognitive changes 1 to 5 years after PD diagnosis
 - Older PD Group (ages 70+) and Early Advanced PD Group (Duration 6-10 years); n=175:
 - 24% recall having experienced cognitive changes before PD diagnosis
 - 20% experienced cognitive changes 5 years or more following PD diagnosis
 - Older PD Group (ages 70+) and Late Advanced PD Group (Duration 11+ years); n=175:
 - 7% recall having experienced cognitive changes before PD diagnosis
 - 60% experienced cognitive changes 5 years or more following PD diagnosis

- The discrepancy between the age and disease duration groups is likely influenced, in part, by the time since diagnosis (i.e., more difficulties recalling personal experiences the more time has transpired from the time of diagnosis, i.e., more remotely vs. more recently). Also, as reported by Copeland and colleagues¹⁷, as the severity of cognition increases, appreciation of and awareness about cognitive symptoms may alter the accuracy of self-report responses.

Everyday Cognition (E-Cog): Perceived change in cognition over time (see Table 2):

1. The experience of cognitive changes was highly reported across age and disease duration-matched groups.
2. The majority of the participants in this survey (66%-77%) indicated that they have experienced “questionable/ occasionally worsening” cognitive change.
3. The Late Advanced Disease Duration Group (PD duration 11+ years) evidenced the greatest perceived change in cognition across domains.
4. Attention was the most frequently reported function that “**consistently worsened**” with increased age and disease duration.
5. Language, Memory, Attention, and Organization, had the highest frequency of perceived change (questionable/ occasional to consistent worsening) within age and disease duration-matched groups.
6. Difficulties with visuospatial functioning and planning are also commonly experienced. Although these difficulties are reported by participants across age and disease duration groups, the difficulties in these domains were not reported in greater frequency as age and disease progress.

Table 2. Cognitive changes over time: The patient’s perspective

	Early PD Group		Advanced PD Group			
	(<6 years duration)		6-10 years duration		11+ years duration	
	Younger (50-69) (n =202-230) ¹	Older (70+) (n =243-273)	Younger (50-69) (n =184-205)	Older (70+) (n = 216-257)	Younger (50-69) (n =231-257)	Older (70+) (n =200-243)
Everyday Cog. Total Average						
Better or no change	14.8%	7.7%	7.3%	5.4%	5.1%	4.9%
Questionable/Occasionally worse	73.0%	74.9%	77.3%	66.1%	70.5%	66.0%
Consistently worse	2.6%	4.1%	2.0%	6.7%	9.9%	10.5%
Memory Average						
Better or no change	40.7%	25.4%	33.5%	21.9%	24.9%	16.2%
Questionable/Occasionally worse	50.5%	60.2%	57.3%	63.7%	58.7%	58.5%
Consistently worse	8.8%	14.5%	9.4%	14.4%	16.4%	25.3%
Language Average						
Better or no change	31.7%	25.7%	21.6%	17.6%	17.3%	14.2%
Questionable/Occasionally worse	56.1%	61.5%	65.5%	66.0%	63.7%	57.8%
Consistently worse	12.2%	12.8%	12.9%	16.4%	19.0%	28.0%
Visuospatial Average						
Better or no change	66.2%	59.9%	66.3%	54.6%	54.2%	47.2%
Questionable/Occasionally worse	30.0%	35.7%	30.6%	37.6%	38.8%	40.7%
Consistently worse	3.8%	4.4%	3.2%	7.9%	7.1%	11.9%

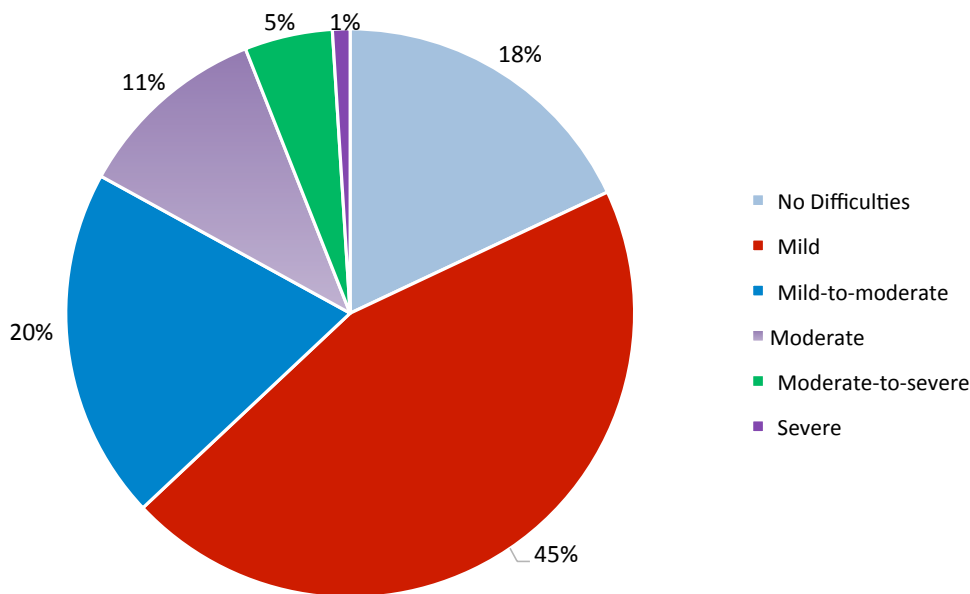
Planning Average						
Better or no change	63.3%	59.8%	61.5%	56.7%	51.8%	46.5%
Questionable/Occasionally worse	31.3%	36.8%	34.9%	34.9%	37.5%	42.6%
Consistently worse	5.4%	3.4%	3.5%	8.4%	10.6%	10.8%
Organization Average						
Better or no change	50.5%	42.8%	46.7%	34.3%	25.5%	25.5%
Questionable/Occasionally worse	38.6%	42.0%	46.2%	48.6%	53.3%	45.5%
Consistently worse	10.9%	15.2%	7.1%	17.1%	21.3%	29.0%
Attention Average						
Better or no change	34.7%	33.3%	31.4%	30.4%	23.9%	25.7%
Questionable/Occasionally worse	42.5%	48.6%	48.5%	43.5%	40.7%	36.9%
Consistently worse	22.8%	17.6%	20.2%	26.1%	35.4%	37.0%

1. The range represents the different number of respondents across cognitive domains.
Note: 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.

CURRENT COGNITIVE STATUS PERCEPTION OF THE PARTICIPANT:

- 82% of the participants of this survey reported experiencing cognitive difficulties currently, with the majority (65%) experiencing mild to mild-to-moderate levels of cognitive difficulties (See Figure 2).

Figure 2. Severity of current cognitive difficulties (N=1403)



- When looking at specific cognitive domains across age and disease duration groups (see Table 3):
 - The least reported cognitive difficulty was the experience of confusion.
 - Memory and Language skills (largely influenced by changes in verbal expression in comparison to difficulties “understanding” others) were the most highly reported cognitive difficulties, followed by slowed processing speed and executive functioning difficulties (management of more complex skills, planning, organizing, difficulties engaging in two tasks simultaneously – i.e., multi-tasking).
 - Regarding Language skills:
 - 84% reported word-finding difficulties (N=1,516)
 - 63% reported difficulties with expression (N=1,523)
 - 47% reported difficulties understanding what others are saying (N=1,520)

- Difficulties in all cognitive domains were reported in greater frequency with age and disease duration-matched groups (i.e., **Younger PD Group** – cognitive difficulties were reported with higher frequency as disease duration increased and **Older PD Group** – cognitive difficulties were reported with higher frequency as disease duration increased).
 - The experience of confusion (albeit of low prevalence for the participants in this study) and difficulties with attention (highly prevalent across age and disease duration-matched groups) demonstrated the least change in symptom frequency across age and disease duration groups.
 - Slowed processing speed and increased difficulties with executive functions appear to be the most notable observed dynamic change as PD progresses.
- Regarding Visuospatial skills:
 - 69% reported having problems with vision (N=1,534)
 - 24% reported difficulties opening eyelids (N=1,530)
 - 48% reported misjudging distances or having misperceptions (N=1,524)

Table 3. Current cognitive status: The patient's perspective

	Early PD Group		Advanced PD Group			
	(<6 years duration)		6-10 years duration		11+ years duration	
	Younger (50-69) (n =222-232) ¹	Older (70+) (n =258-274)	Younger (50-69) (n =187-205)	Older (70+) (n = 237-258)	Younger (50-69) (n =236-258)	Older (70+) (n =223-245)
Confusion Average						
No difficulties	70.7%	63.9%	72.7%	59.3%	61.6%	56.7%
Mild to mild-to-moderate difficulties	26.3%	33.2%	25.4%	31.4%	31.8%	32.3%
Moderate difficulties	1.7%	2.2%	1.0%	3.9%	5.4%	6.1%
Moderate-to-severe to severe difficulties	1.3%	0.8%	1.0%	5.5%	1.2%	4.9%
Attention Average						
No difficulties	28.1%	32.6%	29.6%	25.6%	21.9%	25.2%
Mild to mild-to-moderate difficulties	58.1%	56.3%	55.6%	59.5%	56.6%	53.9%
Moderate difficulties	11.1%	9.9%	11.8%	8.3%	16.5%	15.4%
Moderate-to-severe to severe difficulties	2.6%	1.2%	3.1%	6.7%	4.9%	5.6%
Processing Speed Average						
No difficulties	27.2%	22.5%	24.4%	16.9%	16.0%	16.1%
Mild to mild-to-moderate difficulties	61.0%	63.7%	64.8%	67.1%	62.3%	56.1%
Moderate difficulties	8.5%	10.2%	9.3%	10.2%	16.3%	18.4%
Moderate-to-severe to severe difficulties	3.1%	3.4%	1.6%	5.9%	5.3%	9.3%
Initiation Average						
No difficulties	45.8%	40.5%	44.3%	43.0%	24.6%	27.8%

Mild to mild-to-moderate difficulties	45.9%	51.7%	48.3%	43.2%	60.8%	52.3%
Moderate difficulties	8.0%	6.6%	6.5%	8.8%	12.8%	13.9%
Moderate-to-severe to severe difficulties	0.4%	1.2%	1.0%	5.2%	1.6%	5.9%
Executive Function Average						
No difficulties	28.6%	17.3%	21.8%	13.9%	12.9%	10.0%
Mild to mild-to-moderate difficulties	59.7%	68.5%	69.1%	66.4%	66.2%	57.6%
Moderate difficulties	10.1%	11.8%	7.5%	11.7%	18.0%	23.0%
Moderate-to-severe to severe difficulties	1.3%	2.7%	1.5%	7.7%	2.8%	9.5%
Memory Average						
No difficulties	12.6%	12.0%	15.0%	6.6%	8.5%	8.0%
Mild to mild-to-moderate difficulties	76.9%	72.5%	75.7%	74.8%	72.4%	70.1%
Moderate difficulties	10.7%	13.7%	8.0%	16.2%	17.5%	18.2%
Moderate-to-severe to severe difficulties	0.5%	2.0%	1.0%	2.0%	1.2%	3.5%
Language Average						
No difficulties	15.7%	14.9%	11.8%	11.1%	4.8%	7.7%
Mild to mild-to-moderate difficulties	72.7%	72.1%	75.6%	70.9%	74.0%	61.7%
Moderate difficulties	10.0%	11.9%	11.3%	13.9%	20.0%	24.6%
Moderate-to-severe to severe difficulties	1.7%	1.1%	1.5%	4.4%	1.2%	6.0%
Visuospatial Average						
No difficulties	31.9%	31.9%	25.7%	24.7%	19.5%	14.5%
Mild to mild-to-moderate difficulties	62.3%	61.7%	69.4%	63.4%	67.2%	63.9%
Moderate difficulties	4.3%	6.2%	4.5%	11.2%	11.0%	17.0%
Moderate-to-severe to severe difficulties	1.3%	0.4%	0.5%	0.8%	2.4%	4.6%
1. The range represents the different number of respondents across cognitive domains.						
Note: 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.						

IMPACT OF COGNITION ON EVERYDAY LIFE (See Table 4):

- Across age and disease duration groups, the majority of participants reported experiencing an adverse impact of cognition on day-to-day functions, with 22% (**Younger and Early Disease Duration PD Group**) to 43% (**Older and Late Advanced PD Group**) reporting moderate to extreme impact of cognitive difficulties on day-to-day functions.
- Reports of an adverse impact of cognitive difficulties on day-to-day functions and quality of life increase over time.
 - Cognitive difficulties commonly impact day-to-day functions, relationships with others, engagement in social activities and leisure activities/hobbies, and work.
 - Cognitive difficulties can result in feelings of isolation.
 - For those who have or are exposed to pets, cognitive difficulties do not tend to interfere with spending time with them.

Table 4. Impact of cognition on day-to-day functions: The patient's perspective

	Early PD Group		Advanced PD Group			
	(<6 years duration)		6-10 years duration		11+ years duration	
	Younger (50-69) (n =229-231)*	Older (70+) (n =269-274)	Younger (50-69) (n =202-205)	Older (70+) (n = 250-257)	Younger (50-69) (n =250-257)	Older (70+) (n =233-244)
Day-to-day Function						
Not at all	33.8%	25.7%	26.8%	18.4%	16.9%	16.4%
A little bit	44.6%	48.0%	52.0%	48.4%	45.3%	39.9%
Moderate	15.2%	17.8%	15.3%	20.0%	22.0%	26.6%
Quite a bit to extreme	6.5%	8.6%	6.0%	13.2%	15.7%	17.2%
Relationship with Significant Other						
Not applicable	2.6%	5.8%	6.4%	7.1%	3.2%	5.5%
Not at all	45.5%	36.5%	37.3%	30.7%	28.1%	20.7%
A little bit	35.1%	40.5%	35.8%	35.4%	28.5%	33.3%
Moderate	12.6%	10.9%	13.2%	14.6%	22.1%	21.1%
Quite a bit to extreme	4.4%	6.2%	7.4%	12.2%	18.1%	19.4%
Social Engagement						
Not at all	44.8%	39.8%	35.5%	33.2%	23.1%	21.8%
A little bit	32.2%	38.0%	38.4%	36.8%	33.9%	33.1%
Moderate	17.4%	14.2%	18.7%	14.2%	20.3%	23.0%
Quite a bit to extreme	5.7%	8.0%	7.4%	15.9%	22.7%	22.2%
Feeling Isolated						
Not at all	52.8%	51.3%	46.8%	43.3%	23.0%	27.0%
A little bit	23.1%	29.7%	32.0%	33.7%	35.7%	28.2%
Moderate	17.5%	11.4%	14.3%	11.9%	23.0%	23.2%
Quite a bit to extreme	6.6%	7.7%	6.9%	11.1%	18.3%	21.6%
Leisure Activities						
Not at all	50.0%	43.8%	48.2%	36.5%	27.6%	29.5%
A little bit	29.7%	34.7%	31.2%	36.4%	34.5%	26.1%
Moderate	11.6%	11.3%	13.2%	11.6%	19.0%	20.0%
Quite a bit to extreme	8.6%	10.3%	7.3%	15.5%	19.0%	24.5%
Care or Spend Time with Pet						
Not applicable	28.7%	45.6%	26.7%	40.4%	30.8%	47.4%
Not at all	54.8%	42.6%	58.4%	43.5%	42.4%	31.2%
A little bit	10.0%	7.4%	12.4%	7.5%	13.6%	9.8%
Moderate	5.2%	2.2%	1.5%	5.9%	9.2%	4.7%
Quite a bit to extreme	1.3%	2.2%	1.0%	2.8%	4.0%	6.8%
Ability to Work						
Not applicable	30.7%	40.1%	28.6%	40.5%	31.7%	43.9%
Not at all	27.7%	21.0%	21.7%	19.4%	11.5%	13.5%
A little bit	19.5%	25.0%	20.7%	17.1%	19.0%	16.9%
Moderate	8.7%	6.6%	12.3%	9.1%	14.7%	9.3%
Quite a bit to extreme	13.4%	7.3%	16.8%	13.9%	23.0%	16.5%

Quality of Life						
Not at all	34.2%	28.5%	25.3%	25.8%	12.7%	18.4%
A little bit	39.0%	47.0%	44.1%	41.4%	40.9%	30.3%
Moderate	16.5%	14.8%	17.8%	16.0%	22.6%	24.4%
Quite a bit to extreme	10.4%	9.6%	12.9%	16.8%	23.8%	26.9%

* The range represents the different number of respondents across domains.

ACTIVITIES OF DAILY LIVING/GENERAL FUNCTIONAL CAPABILITY (See Table 5):

- Note, functional difficulties reported in this section may represent difficulties resulting from both motor (i.e., tremor, coordination difficulties, slowness of movement, etc.) and/or non-motor difficulties (cognitive difficulties, fatigue, pain, depression, anxiety, etc.).
- The **Older PD Group** had greater reports of functional difficulties when compared to the **Younger PD Group** when matched on disease duration.
- Housekeeping and Food Preparation were the domains in which functional difficulty was most frequently reported across age and disease duration-matched groups.
- The majority of participants in the **Younger and Early Disease Duration Group** reported functional independence, with the greatest difficulties involving Housekeeping, Food Preparation, and Shopping.
- The majority of participants in the **Older and Late Advanced Disease Duration Group** reported the need for assistance with Housekeeping, Food Preparation, Transportation and Shopping.
- The instrumental activity of daily living least impacted by cognition is use of the telephone.
- There was a strong significant relationship between functional difficulties and severity of cognitive difficulties.

Table 5. Functional independence in activities of daily living: The patient's perspective

	Early PD Group (<6 years duration)		Advanced PD Group			
	Younger (50-69) (n =219)	Older (70+) (n =242)	6-10 years duration		11+ years duration	
			Younger (50-69) (n =195)	Older (70+) (n = 226)	Younger (50-69) (n =244)	Older (70+) (n =220)
Telephone						
Independent	97.0%	93.7%	97.0%	86.6%	94.1%	80.2%
Mild assistance	1.7%	2.2%	1.0%	3.1%	3.2%	8.3%
Major assistance	1.3%	1.5%	1.0%	5.9%	1.2%	7.0%
Completely dependent	0.0%	2.6%	1.0%	4.3%	1.6%	4.5%
Shopping						
Independent	80.4%	74.0%	77.6%	58.3%	59.8%	44.9%
Mild assistance	13.0%	11.7%	12.4%	18.3%	17.7%	14.8%
Major assistance	5.2%	12.1%	7.0%	13.5%	20.4%	25.8%
Completely dependent	1.3%	2.3%	3.0%	9.9%	2.0%	14.4%
Food preparation						
Independent	78.2%	65.3%	77.1%	54.0%	65.3%	40.2%
Mild assistance	9.6%	12.6%	11.4%	16.5%	15.5%	16.2%
Major assistance	7.4%	12.6%	9.0%	16.1%	12.4%	19.7%
Completely dependent	4.8%	9.5%	2.5%	13.3%	6.8%	23.9%

Housekeeping						
Independent	71.5%	58.6%	62.9%	43.0%	49.8%	30.1%
Mild assistance	0.0%	3.0%	1.0%	1.2%	0.8%	1.3%
Major assistance	22.8%	29.7%	33.7%	37.3%	37.8%	38.5%
Completely dependent	5.7%	8.7%	2.5%	18.5%	11.6%	30.1%
Laundry						
Independent	90.7%	80.3%	91.0%	68.9%	84.5%	57.6%
Mild assistance	N/A	N/A	N/A	N/A	N/A	N/A
Major assistance	4.4%	9.1%	5.0%	10.7%	6.4%	10.5%
Completely dependent	4.9%	10.6%	4.0%	20.5%	9.2%	31.9%
Transportation						
Independent	90.4%	78.4%	84.7%	64.3%	71.0%	40.3%
Mild assistance	1.3%	2.3%	5.4%	4.8%	5.6%	8.9%
Major assistance	5.7%	13.6%	9.4%	20.3%	16.7%	36.0%
Completely dependent	2.6%	5.7%	0.5%	10.7%	6.7%	14.8%
Medication Management¹						
Independent	91.3%	85.4%	95.0%	76.1%	88.9%	63.8%
Mild assistance	7.4%	8.6%	4.0%	12.5%	7.1%	20.4%
Completely dependent	1.3%	6.0%	1.0%	11.4%	4.0%	15.7%
Financial Management²						
Independent	82.9%	77.4%	82.2%	66.8%	70.3%	53.0%
Major assistance	14.5%	15.2%	15.8%	21.6%	25.8%	28.0%
Completely dependent	2.6%	7.4%	2.0%	11.6%	3.9%	19.1%
1. Medication Management: Major Assistance was not applicable						
2. Financial Management: Mild Assistance was not applicable						

ASSESSMENT AND TREATMENT OF COGNITION:

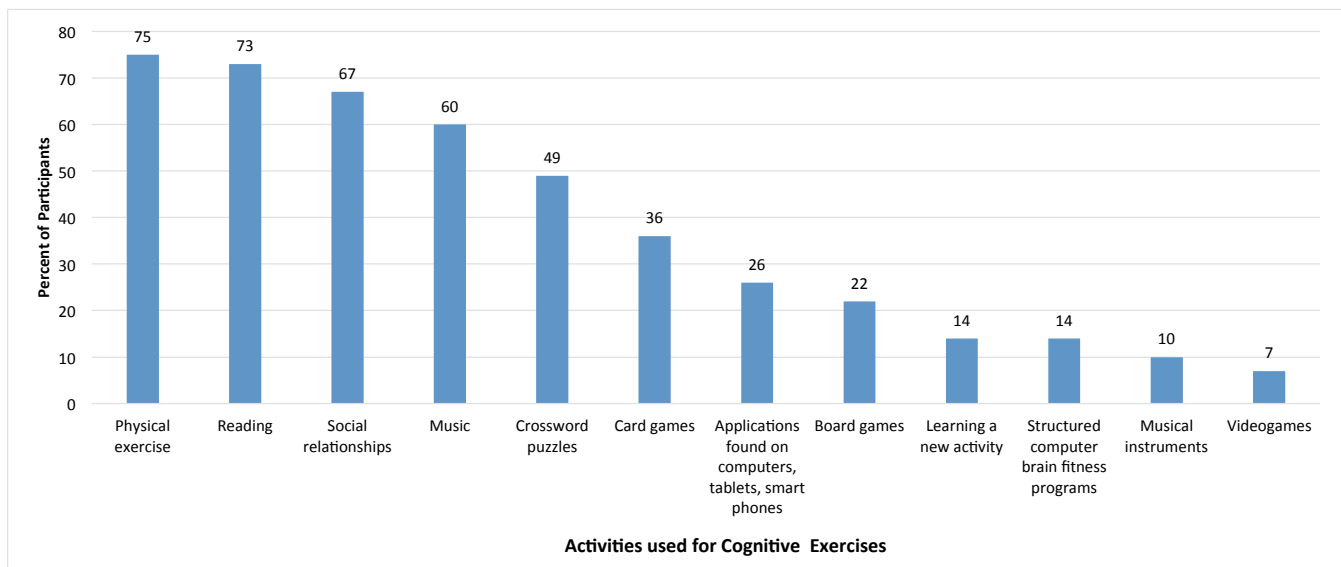
- 42% of 1,147 individuals reporting cognitive difficulties reported having participated in “formal assessment” of cognitive functioning.
- The percent of participants who have undergone a cognitive assessment by the following specialists (N=1,536):
 - Neurologist: 24%
 - Neuropsychologists: 17%
 - Speech Therapist (rehabilitation specialist): 8%
 - Occupational Therapist (rehabilitation specialist): 6%
 - Psychiatrists: 5%
 - Primary Care Physician: 4%
 - Other: 4%
- 16% reported taking medications for cognitive difficulties (see Table 6)
 - To what extent are/were the medications perceived to be helpful:
 - 11% reported “not at all”
 - 27% reported “a little bit”
 - 22% reported “moderately”
 - 14% reported “quite a bit”
 - 3% reported “extremely”
 - 3% reported “do not know”

Table 6. Common medications prescribed for cognitive difficulties (N=1,224-1,288):

Medication	Current Use	Past Use	Never Used	Do Not Know
Donepezil (Aricept)	5%	3%	91%	<1%
Rivastigmine (Exelon)	4%	2%	93%	<1%
Galantamine (Razadyne)	<1%	<1%	98%	<1%
Memantine (Namenda)	4%	<2%	94%	<1%
Modafanil (Provigil)	<1%	<2%	98%	<1%
Methylphenidate (Ritalin)	<1%	1%	98%	<1%
Amphetamine (Dexedrine)	<1%	1%	98%	<1%

- 7% of 1,479 participants reported that non-medication-based treatment was recommended by a treatment provider; 10% were not sure if such a recommendation was made.
 - The most frequently reported activities that the participants consider cognitive exercises include exercise, reading, social relationships, and music, which are used by more than 50% of the participants (see Figure 3).
 - To what extent are the cognitive exercises perceived to be helpful (N=1,333):
 - 7% reported “not at all”
 - 29% reported “a little bit”
 - 28% reported “moderately”
 - 27% reported “quite a bit”
 - 9% reported “extremely”

Figure 3. Activities used for cognitive exercise/stimulation as reported by the participants



Themes from the comments made by survey participants:

- Comfort and validation in perceived experiences with cognitive changes. One participant wrote, “...I found it oddly comforting to see this list that adds definition to what I’m observing.”
- Many life experiences and other clinical variables can impact cognitive functioning (i.e., secondary illness; pain; anxiety; medication effects)
- Difficulties with cognitive functioning (i.e., slowed processing speed and difficulties “multi-tasking” adversely impact community and work involvement.

- Cognitive difficulties are socially isolating.
- Cognitive difficulties prevent individuals from driving, due to – for example – “fltering executive functions. i.e., I can’t decide what to do in complex driving scenarios.”
- Engagement in “organized classes” is beneficial [due to cognitive difficulties].
- Sensory changes, such as vision disturbances (double vision, visual acuity changes, difficulty opening eyelids) and hearing difficulties can lead to others perceiving cognitive changes (misattribution). “Reduced communication abilities [due to hearing difficulties] may make cognitive changes appear worse than they are.”

SUMMARY AND DISCUSSION

In recent decades, neuroscientists have become increasingly aware that cognitive dysfunction is not only an expected change for many individuals with Parkinson’s disease (PD), it can also be one of the most concerning and debilitating symptoms of PD, significantly adversely impacting 1. one’s engagement in daily activities and 2. quality of life. For many clinicians, patients, and family and care providers, however, the concepts and categories applied to discussions of cognitive changes are unclear or can be misunderstood. Appreciation and awareness of patient perspectives of their cognitive difficulties and their perceived impact on day-to-day life are indicated. Despite research identifying reduced insight into or appreciation of cognitive deficits as a challenge in self-report¹⁷, understanding patients’ perspectives about their experiences has important implications for health care practices, particularly in the context of a “patient-centered” approach to care. For example, clinicians can work collaboratively with the patient and family to identify which symptoms are priorities for treatment or evaluating whether or not a treatment is effective in a way that is meaningful for their daily functioning.

TAKE HOME POINTS FROM THIS SURVEY:

It is important to understand the difference between normal aging, Mild Cognitive Impairment, and PD Dementia:

Normal Aging: Cognitive strengths, weaknesses and difficulties are quite diverse in the “normal” aging process, and certain cognitive changes are commonplace, including changes in processing speed and certain memory, language, visuospatial, and executive function abilities. When differentiating normal aging from cognitive impairment that is classified as “abnormal,” cognitive changes with normal aging are small and should not result in impaired function¹.

Mild Cognitive Impairment (MCI): MCI involves cognitive decline that is typically insufficient to affect daily functions (i.e., at home, in the community, at work), though difficulties may be present². Such difficulties can be concerning to and perceived as significantly hindering for individuals who are aware of their difficulties/ changes in cognition. MCI is an intermediate level of severity between the expected cognitive declines of normal aging and the more serious decline of dementia. It can involve problems with memory, language, attention and concentration, multi-tasking, and judgment that are greater than normal age-related changes.

*Importantly, MCI for individuals with PD does not necessarily progress to PD Dementia.

PD Dementia: A classification used when cognitive deficits (i.e., memory and other cognitive functions) are severe enough to impair engagement and completion of activities of daily living (i.e., managing schedules, preparing food/eating, engaging in house chores, managing medication, driving, etc.). It is important to make the distinction between interference in activities of daily living due to motor disturbance versus difficulties with cognition, the latter being required for a diagnosis of dementia².

Objective 1: To understand the patient’s perspective about changes in his or her cognition.

Cognitive Changes in PD:

- Cognitive changes are highly prevalent in and are reported by individuals with PD.
- 82% of the participants reported experiencing cognitive difficulties at the time of completing this survey, with

the majority (65%) experiencing mild to mild-to-moderate levels of cognitive difficulty.

- The most frequently reported cognitive difficulties were memory and language skills, followed by slowed processing speed and difficulties with executive functioning (management of more complex skills, planning, organizing, difficulties engaging in two tasks simultaneously – i.e., multi-tasking).
- Difficulties in all cognitive domains were reported in greater frequency with age and disease progression.
 - The experience of confusion (albeit of low prevalence for the participants in this study) and difficulties with attention (highly prevalent across age and disease duration-matched groups) demonstrated the least change in reported frequency across age and disease duration groups.
 - Slowed processing speed and increased difficulties with executive functions appear to be the most notable observed dynamic changes as PD progresses.
 - Such findings are consistent with research^{2,22,23}, showing that difficulties with attention, executive functioning, memory, and visuospatial functions are common for individuals with PD.
 - Speech changes are also highly prevalent in individuals with PD²⁴ and involve both motor changes (i.e., lower volume, hoarseness, and slurred speech expression) and cognitive change (i.e., word-finding problems). The data from this survey found:
 - 84% reported word-finding difficulties
 - 63% reported difficulties with expression
 - 47% reported difficulties understanding what others are saying
- A considerable number of participants reported that they experienced cognitive changes early in their disease course, even prior to their PD diagnosis.
 - However, the number of individuals who reported having cognitive difficulties prior to diagnosis was considerably lower amongst those with a longer duration of PD. For example, 33% and 38% of the **Younger and Older PD Groups**, respectively, whose disease duration was **0-5 years** reported onset of cognitive changes prior to diagnosis. In contrast, 11% and 7% of the **Younger and Older PD groups**, respectively, whose disease duration was **11+ years** reported onset of cognitive changes prior to diagnosis.
 - Two plausible explanations for this finding include 1. Disease progression may adversely impact accurate recall of remote information (e.g., difficult to recall what cognition was like prior to diagnosis), and/or 2. Disease progression resulting in increased severity of cognitive difficulties may adversely impact level of insight or awareness and may alter the accuracy of self-report responses¹⁷.
- The **Late Advanced Disease Duration Group** (PD duration 11+ years) reported the greatest perceived change in cognition across cognitive domains.
 - Language, Memory, Attention, and Organization, had the highest frequency of perceived change within age and disease duration-matched groups. The domain of Attention had the highest reports of “consistent worsening” over time.
 - Difficulties with visuospatial functioning and planning are also commonly experienced. Although these difficulties are reported by participants across age and disease duration groups, the difficulties in these domains were not reported in greater frequency as age and disease progress.

Objective 2: To understand how current cognitive difficulties can impact day-to-day life experiences.

- Across age and disease duration groups, the majority of participants reported that cognitive difficulties adversely

impact day-to-day functions, with 22% (**Younger and Early Disease Duration PD Group**) to 43% (**Older and Late Advanced PD Group**) reporting a moderate to extreme impact of cognitive difficulties on day-to-day functions.

- Not surprisingly, there was a strong relationship between cognitive impairment and the impact of cognitive difficulties on day-to-day functions. The greater the cognitive deficits, the greater the adverse impact on day-to-day functions.
- Participants reported an increased frequency of cognitive difficulties having an adverse impact on day-to-day functions and quality of life with increased age and disease duration.
 - Cognitive difficulties commonly impact day-to-day functions, relationships with others, engagement in social activities and leisure activities/hobbies, and work.
 - Cognitive difficulties can result in feelings of isolation.
- There was a strong and significant relationship between severity of cognitive difficulties and functional difficulties with activities of daily living (i.e., shopping, food preparation, housekeeping, laundry, medication management, financial management, and transportation). The greater the cognitive deficits, the greater the functional difficulties with activities of daily living.

Objective 3: To understand the extent that people with PD perceive themselves as having 1. undergone assessment of cognitive functioning and 2. received treatment for cognitive difficulties.

- Less than half of the participants reported having had a formal assessment of cognition. Whereas treatment guidelines for PD include annual assessment of cognition²⁵ (i.e., cognitive screening), the patients perceive that this assessment does not take place. Some reasons for this perspective may include 1. Not all clinicians follow the American Academy of Neurology guidelines regarding PD care; 2. Patients may not be informed that they were undergoing a cognitive assessment or screen (i.e., during their interaction with the physician); and, 3. Patients may not recall that they underwent an assessment.
- Neurologists and neuropsychologists are the most common clinicians conducting formal cognitive assessments (24% and 17% of the participants report having had a formal cognitive assessment by a neurologist and neuropsychologist, respectively).
- The vast majority of the participants in this study indicated that they have not been prescribed medications for cognitive difficulties. Many of the participants who have been prescribed such medication reported perceived benefit.
- Non-medication-based interventions are also used for individuals with PD.
 - Individuals with PD are not commonly referred for formal cognitive rehabilitation therapy.
 - More than 50% of the participants used cognitive exercises, the most frequent being physical exercise, reading, social relationships, and music.

GENERAL RECOMMENDATIONS:

1. Given the prevalence of cognitive difficulties experienced by individuals with PD, seeking education about cognition and PD is recommended:
 - i. Have a conversation about cognition with a specialist in movement disorders, (i.e., a neurologist, neuropsychologist, or psychiatrist).
 - ii. Multiple factors can contribute to cognitive changes. When some symptoms are treated effectively improvement in cognitive functioning may result. Talk to your doctor about treating symptoms that can impact cognitive functioning/mental efficiency:
 1. Sleep disturbance
 2. Fatigue
 3. Pain

4. Psychological factors (i.e., depression, anxiety, stress)
 5. Malnutrition
 6. Medications that adversely affect cognition.
- iii. Monitor and treat sensory changes (i.e., vision and hearing) that can interfere with cognitive processing. Note that perceived changes in cognition and functional difficulties may actually be accounted for by hearing or visual disturbances.
 - iv. Many individuals benefit from a team-based approach for education about PD symptoms and symptom management. Teams may include: Movement Disorder Specialist, Psychiatrist, Psychologist/ Neuropsychologist, Registered Dietitian/Nutritionist, Rehabilitation Therapists (i.e., Physical Therapist, Occupational Therapist, Speech Therapist), Pulmonologist and Respiratory Therapists. Watch for patient education programs conducted by local and national organizations, including conferences, support groups, on-line programs, and webinars that have speakers of various disciplines speaking about PD management.
 - v. Participating in a neuropsychological assessment (conducted by a neuropsychologist) may be helpful in understanding the cognitive and psychological status of individuals with PD that can then guide treatment.
2. When addressing assessment and treatment recommendations, it is important to keep in mind that individual cognitive capabilities should be considered in relation to the specific context of the patient's day-to-day life and needs. The American Academy of Neurology indicated that it is important to identify cognitive impairment in terms of the patient's care and responsibilities within the home, community, /or workplace²⁵.
 - a. For example, a cognitive assessment that is designed to assist an individual who may need accommodations at work should differ from a cognitive assessment to clarify how much assistance an individual requires with the completion of activities of daily living in the home (i.e., cooking, medication management, financial management, etc.).
 3. Cognitive training and cognitive rehabilitation may be of benefit to individuals with PD. Primary treatment providers for cognition include speech therapists, neuropsychologists, and occupational therapists. Notably, there is limited scientific evidence supporting such treatments for individuals with PD. Although such research is in its early stages, clinicians who specialize in treating PD should be able to discuss what techniques are scientifically proven to help with day-to-day functions^{26,27}. For example, learning compensatory techniques for real-world function has been proven to be more beneficial to day-to-day functional improvement than "brain exercises" in a clinician's office or with on-line computerized brain-game training²⁸. Moreover, learning specific techniques for specific tasks (e.g., how to button a shirt) has been shown to be more helpful than conduction of exercises that are purported to generalize to real-world activities (i.e., improved performance on brain games has not generalized to improved function in day-to-day activities).
 4. Cognitive-behavioral psychotherapy for individuals with PD that involves family or care providers (if appropriate) can be used to address adjustment to cognitive difficulties and psychosocial stressors and related coping strategies.
 5. Service dogs and animal-assisted therapy is a growing field that uses dogs and other animals to help people cope with and address health problems and symptoms.
 - a. Service dogs trained to work with people with Parkinson's can help their owners maintain balance while walking, or alert a family member after a fall. They can also be trained to help people with Parkinson's move when experiencing gait freezing or stand up from from a chair or after a fall²⁹.
 - b. Having a pet more generally and engaging in animal-assisted activities have a more general purpose, such as providing companionship, comfort, and enjoyment, and creating meaning and purpose. Caring for a pet can be as important as caring for a family member³⁰.
 6. Medications that facilitate psychological well-being, in conjunction with psychotherapy, may be helpful for participants who suffer from depressive or anxiety that impacts cognitive functioning. However, caution is

indicated when it comes to selecting certain medications, as some medications, e.g., benzodiazepines, anticholinergic medications, dopamine agonists, can cause or worsen cognitive and psychological symptoms. It is recommended that use of psychotropic medications be monitored by a specialist in psychiatric medications for individuals with PD.

7. Medications for cognitive impairment may be helpful (e.g., cholinesterase inhibitors, such as Rivastigmine (Exelon). Talk to your doctor about the appropriateness and potential benefit of such medications.
8. Interventions that improve on sleep and fatigue management may help improve cognitive functions.
 - a. Sleep disturbance is common in PD. Talk to your doctor about any sleep difficulties you may have and determine if additional assessment is needed and what treatments may be of benefit, if indicated.
 - b. Given that fatigue has been found to be most common in the afternoon, scheduling one's day to incorporate more demanding tasks in the morning may help improve performance and endurance in activities. Similarly engaging in more restful and less demanding tasks in the afternoon may be helpful.
9. Using resources in the community, such as support groups, exercise groups, yoga classes, public parks, and the like, can help individuals participate in activities that may help facilitate cognitive engagement and purposeful living, which can result in a favorable impact on physical, cognitive, and psychological well-being.
10. Continued research on and treatments for cognitive difficulties is needed.

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