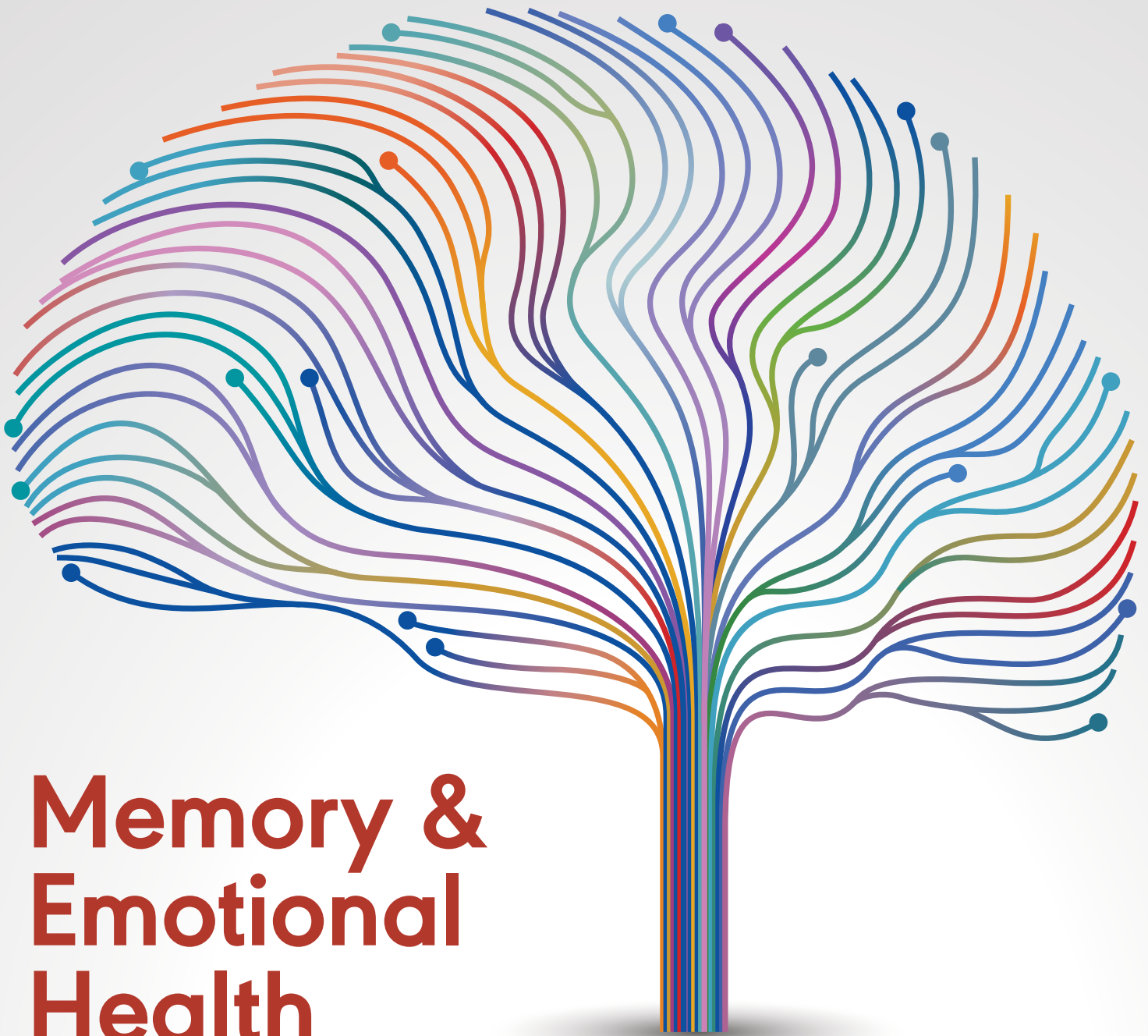


PARKINSON ALLIANCE

Fall 2021



Memory & Emotional Health

in Parkinson's Disease

Memory and Emotional Health in Parkinson's Disease

INTRODUCTION

In the last decade, non-motor symptoms have been in the spotlight of Parkinson's Disease (PD) research. While there are many non-motor symptoms that impact day-to-day functions, relationships, and quality of life, this report highlights memory functioning and emotional health. The sections that follow provide an introductory context to understanding memory symptoms and emotional symptoms for individuals with PD.

Memory:

- “Central to all cognitive functions and probably to all that is characteristically human in a person's behavior is the capacity for memory, learning, and intentional access to this knowledge store.”¹ While memory is a complex function tied to different “systems” in the brain, a detailed description of the systems is beyond the scope of this report. For the sake of this report, the stages of memory can be described as having the following processes: 1. Registering information or sensory input (involving “acquisition” and “encoding” the active process of learning and absorbing information), 2. storing the information (the consolidation phase where memories are converted from temporary to long-term storage), and 3. pulling out information to conscious awareness (the retrieval phase).
- Individuals with PD most commonly have difficulties with “**acquisition**” (i.e., acquiring information and getting the information into storage in order to be remembered later) and “**retrieval**” functions (i.e., difficulty remembering details or finding the right words to say “I know what I want to say, I just can't find the right words”)². “Forgetfulness” for individuals with PD is commonly attributable to difficulties with the acquisition and retrieval functions, both being impacted by difficulties with attention and more complex thinking skills known as executive functioning.

Subjective and objective reports of memory difficulties:

Memory difficulties can be caused by a number of factors, such as changes in the brain (chemicals or structure), emotional disturbance, high stress related to medical problems and functional difficulties, sleep disturbance, fatigue, pain, and medication effects. Treatment of these respective causes may improve memory³⁻⁶. **Subjective memory impairment** can be described as an individual's perception of how their memory is functioning⁷. While memory difficulties can be evident by objective assessments, many individuals report memory difficulties from their subjective perspective, meaning that even without objective evidence perceived memory difficulties are experienced by an individual. Subjective memory complaints (SMCs) are commonly reported by patients with PD in the clinical setting and clinicians often rely heavily on such complaints when deciding whether or not to take action/treatment.

Emotional health and PD:

Emotion disturbance (e.g., depression and anxiety) affects up to 40% of individuals with PD⁸. Development of these symptoms can stem from both biological factors and adjustment difficulties. Biological contributions of mood symptoms include chemical changes in the brain^{9,10}. Life stressors associated with adjustment difficulties may include increased relationship stressors (i.e., spouse, family, friends), feelings of stigma¹¹, career changes (e.g., unemployment or early retirement due to disability), reduced engagement in hobbies, and reduced independence (e.g., in ability to drive).

Relationship between memory impairment, emotional disturbance, and quality of life:

Emotional disturbance has a strong relationship with memory difficulties and can be a contributing factor to changes in memory. In fact, when emotional distress or symptoms of depression and anxiety are treated, memory functions may improve^{4,12}. Memory functioning and emotional status are distinctly associated with quality of life among people with PD. Specifically, research has found that individuals with memory impairment due to PD reported lower quality of life in the realms of communication, stigma, and social support¹³. Anxiety and depression have also been found to be strong predictors of reduced quality of life in individuals with PD.

Coping Techniques:

With regard to management of cognitive impairment in PD, medications such as Exelon have been found to be helpful^{14,15}. Cognitive rehabilitation programs have also been found to improve memory^{16,5}. Similarly, physical exercise programs have been found to improve memory and other thinking skills in individuals with PD^{3,17}. Mindfulness training may also assist with improving memory and health-related quality of life in individuals with PD^{18,19}.

Pharmacological interventions and cognitive-behavioral therapy can be successful in addressing emotional symptoms of PD²⁰, thereby also improving memory functions for some individuals. Increased engagement in adaptive, proactive coping strategies (e.g., planful problem solving coping) has been found to be related to improved quality of life, even with those who have memory difficulties²¹.

OBJECTIVES

- To gain insights about the person with Parkinson's (PWP) subjective report of memory difficulties and emotional health.
- To identify common coping strategies PWP use to cope with memory difficulties and emotional disturbance.
- To provide general comments about and recommendations pertaining to memory functioning and emotional well-being.

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.
- There were 444 individuals who participated in this survey.
- Participant representation was across 38 states in the United States, with New Jersey (19%), California (11%), New York (11%), Florida (9%), Texas (7%), Pennsylvania (8%), Arizona (6%), Minnesota (2%), Colorado (2%), Tennessee (2%), Ohio (1%), Michigan (1%), and Massachusetts (1%) having the most participants. There were 12 (3%) international participants.

Questionnaires/Measures:

1. The Parkinson Alliance Demographic and Clinical Questionnaire, 2. Metamemory in Adulthood Questionnaire²²⁻²⁴, 3. Patient Reported Outcome Measure – General Cognitive Concerns²⁵, 4. Patient Reported Outcome Measure – Depression (Short Form)²⁵, 5. Patient Reported Outcome Measure – Anxiety (Short Form)²⁵.

The Parkinson Alliance Demographic and Clinical Questionnaire: The self-report questionnaire inquired about basic demographic information (e.g., gender, race/ethnicity; marital status, education) as well as pertinent clinical information pertaining to memory, emotional health, coping, and quality of life.

Metamemory in Adulthood Questionnaire (MIA22-24).

The MIA contains 20 items measuring knowledge and attitude about one's memory. Two subscales were used in this survey: 1. MIA Change subscale, which assesses perceived memory changes over the past 5 years (e.g., 1 = agree strongly to 5 = disagree strongly) 2. MIA Capacity subscale, which assesses the perception about one's memory ability. Higher scores reflect greater knowledge and more favorable attitudes about memory.

Patient-Reported Outcomes Measurement Information System (PROMIS) - Applied Cognition - General Concerns scale. 25 The PROMIS Applied Cognition-General Concerns scale measures subjectively experienced cognitive functioning during the prior seven days. Participants rate their responses using a scale ranging from 1 (Not at all) to 5 (Very much). A total raw score ranging from 8 to 40 scores is calculated by summing participants' responses to each item. Higher scores indicate perceived better cognitive functioning.

PROMIS Depression Scale: 25 This scale measures self-reported depression during the prior seven days. Participants rate to what extent they experience depression-related symptoms using a scale ranging from 1 (never) to 5 (always). A total raw score ranging from 8 to 40 score is calculated by summing participants' responses to each item. Higher scores indicate higher levels of depression.

PROMIS Anxiety Scale: 25 This scale measures self-reported anxiety during the prior seven days. Participants rate to what extent they experience anxiety-related symptoms using a scale ranging from 1 (never) to 5 (always). A total raw score ranging from 8 to 40 score is calculated by summing participants' responses to each item. Higher scores indicate higher levels of anxiety.

Comparisons based on age and disease duration groups:

- **AGE:** For the purpose of the survey report, age groups were divided into a **Younger PD group** (≤ 69 years of age) and an **Older PD group** (≥ 70 years).
- **DISEASE DURATION:** Research pertaining to individuals with PD has indicated that the average time from symptom onset to development of motor complications was 6 years^{26,27}. Research has divided groups into **Early PD** (<6 years) and **Advanced PD** (6+ years) to define a valid partition between early and advanced disease states.

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 cognitive difficulties become more apparent, may have reduced insight/awareness into or appreciation of their difficulties, 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 perceived stress, resilience, and quality of life.

RESULTS

- The summary of the demographic information and clinical characteristics of the participants in this study can be found in Table 1.
 - There were 444 individuals who participated in this survey.
 - The average age of the participant was 72 years, with an average disease duration of 11 years.
 - Gender was equivalent for male and female participants.
 - The majority of the participants were White.
 - The majority were married and living with someone.
 - 61% the participants reported having a college degree or graduate degree.

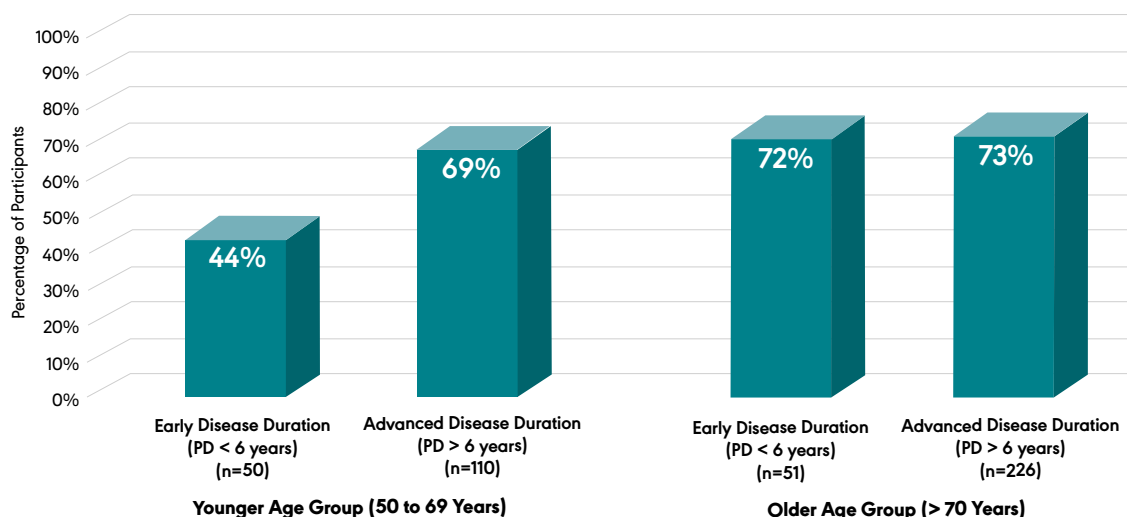
Table 1: Demographics and clinical features of the participants (N=444)

	(Mean, Range, and percentage)
Average Age in Years (range)	72 years (50-101 years)
Duration of PD in Years (range)	11 years (0 to 45 years)
Average Age of PD Diagnosis (range)	60 years (30-83 years)
Male	50%
Female	50%
Married	72%
Lives with Someone	82%
Ethnicity	
Caucasian	95%
African American	2%
Hispanic	1%
Other:	2%
Education	
<12 years	3%
High School	10%
Some College or Associate Degree	26%
College	28%
Graduate/Advanced Degree	33%

SUBJECTIVE MEMORY DIFFICULTIES

- As age increases, the vulnerability of perceived memory difficulties also increases (See Figure 1).
- There was a significantly greater discrepancy between **Early** and **Advanced PD groups** within the **Younger PD group**, reflecting that as disease duration increases, there are greater risks for experiencing perceived memory difficulties.

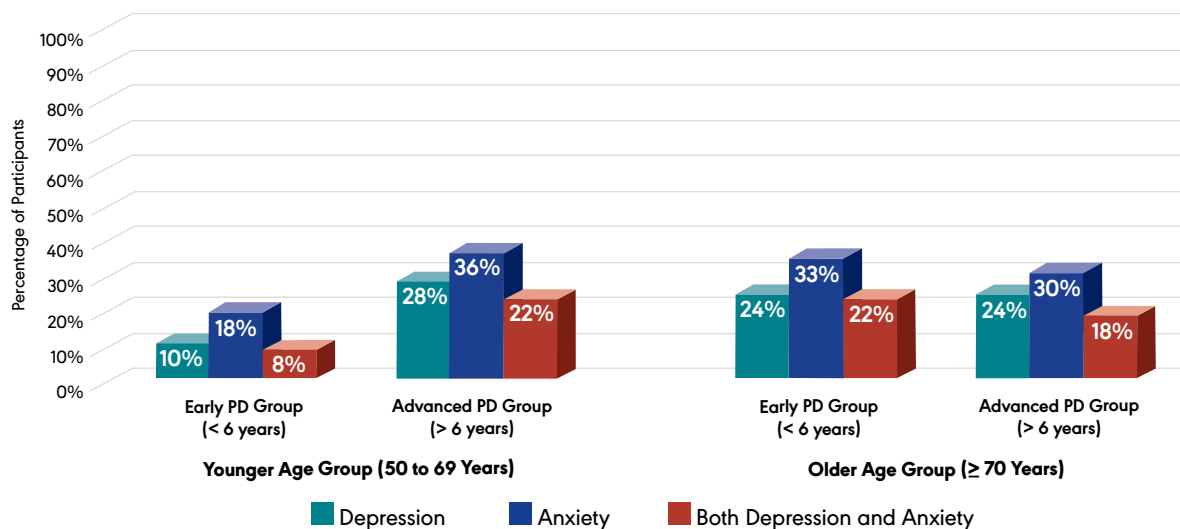
Figure 1: Participants reporting memory difficulties that interfere with daily activities



EMOTIONAL HEALTH

- 23% of the participants reported elevated levels of depression.
- 31% of the participants in the study reported elevated levels of anxiety.
- As can be seen in Figure 2:
 - As disease duration increases in the **Young PD group**, the **Advanced Disease Duration PD group** reported significantly more symptoms of depression and anxiety than the **Early Disease Duration PD group**.
 - In the **Older PD group**, emotional disturbance for both the **Early and Advanced Disease Duration PD group** was comparable.

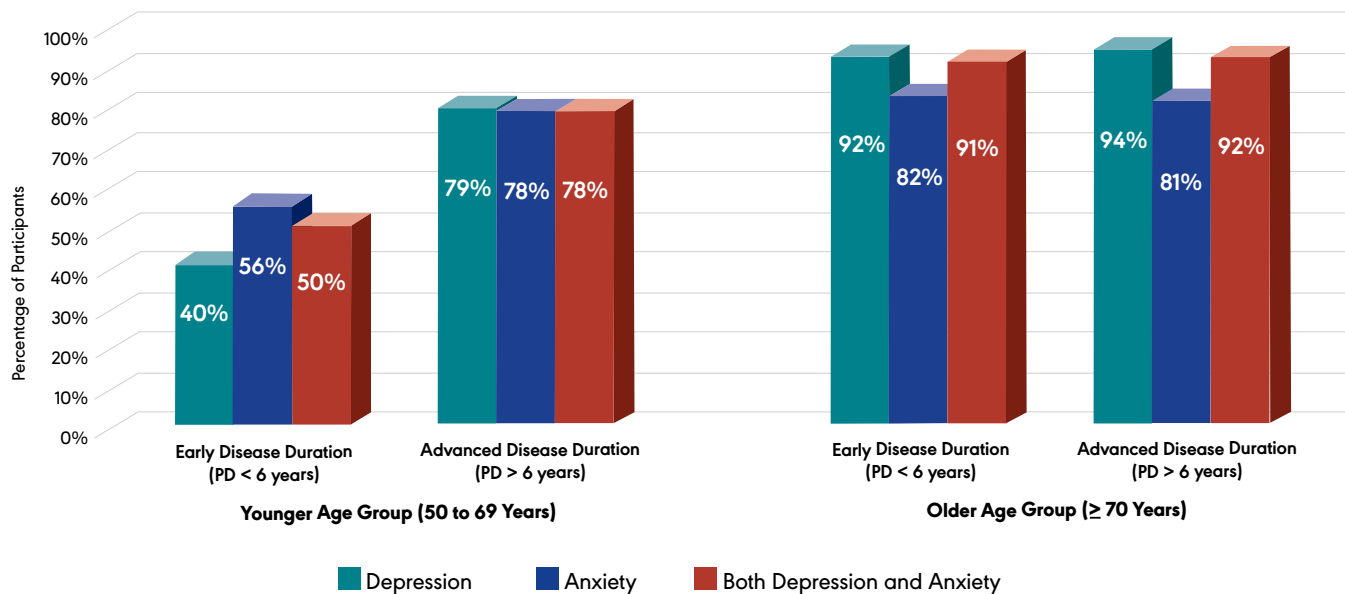
Figure 2: Participants reporting depression and anxiety



Memory Difficulties and Emotional Disturbance

- Figure 3 highlights the impact of emotional disturbance on perceived memory difficulties. As compared to Figure 2, Figure 3 shows that individuals with anxiety and depression report memory problems in far greater frequency than those individuals who do not have emotional disturbance.
- As age and disease duration increases, there is a significantly greater number of individuals experiencing combined depression, anxiety, and memory difficulties.

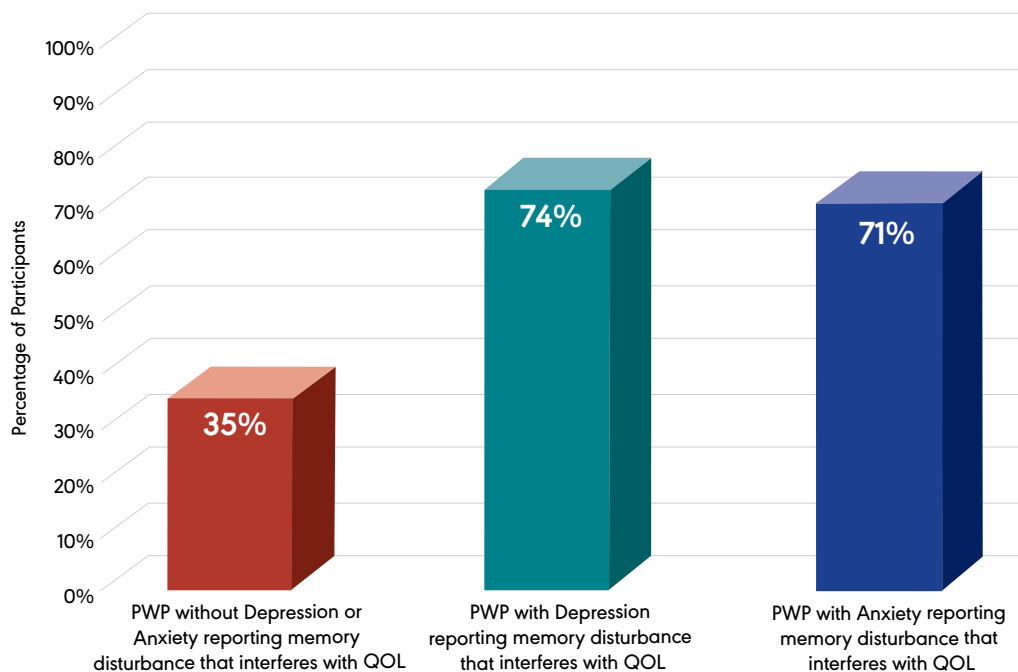
Figure 3: Memory difficulties reported by participants experiencing emotional disturbance



QUALITY OF LIFE

- Memory difficulties interfere with quality of life (QOL) for a large number of the participants.
- Memory difficulties that interfere with quality of life increased as age and disease duration increased.
- **Individuals experiencing depression and anxiety reported that memory difficulties interfered with QOL in greater frequency than those without emotional disturbance (see Figure 4).**

Figure 4: Memory difficulties interfere with QOL with and without emotional disturbance (N=444)



* Figure reflects memory difficulties interfering with QOL the majority of the time

ASSESSMENT, TREATMENT, AND COPING

- Up to 25% of the participants reported awareness about a formal assessment of memory, with primary assessments occurring by a neurologist, followed by a neuropsychologist, internal medicine doctor/ Primary Care Physician, psychiatrist, speech language pathologist, or occupational therapist.
- 14% reported having a medication prescribed for memory difficulties.
- 6% reporting participation in cognitive rehabilitation.
 - Cognitive rehabilitation refers to a specific treatment approach that aims to restore cognitive functioning or to aid in teaching compensatory techniques to increase function in day-to-day activities.

COPING TECHNIQUES

- The top 5 MEMORY coping techniques used by the participants in this study included keeping items in plain sight, using appointment books, making lists, using reminder notes, and creating a daily schedule (see Figure 5).
- The top 5 EMOTIONAL coping techniques used by the participants in this study included connection with others, distraction, exercise, managing attitude, and gratitude statements (see Figure 6).
- Coping strategies had a moderate to strong relationship with emotional distress and memory, such that those reporting engagement in more adaptive coping behaviors also reported less depression or anxiety and better memory.

Figure 5: Coping Techniques to Improve Memory

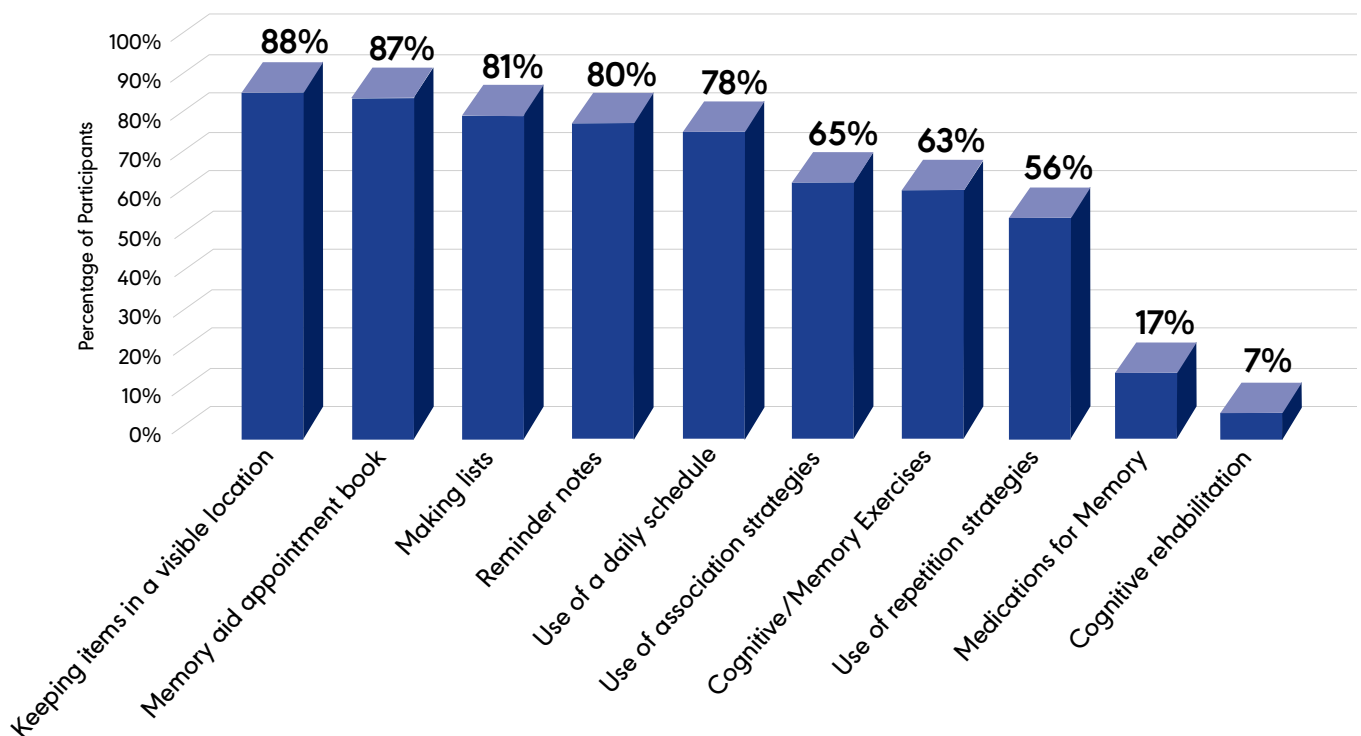
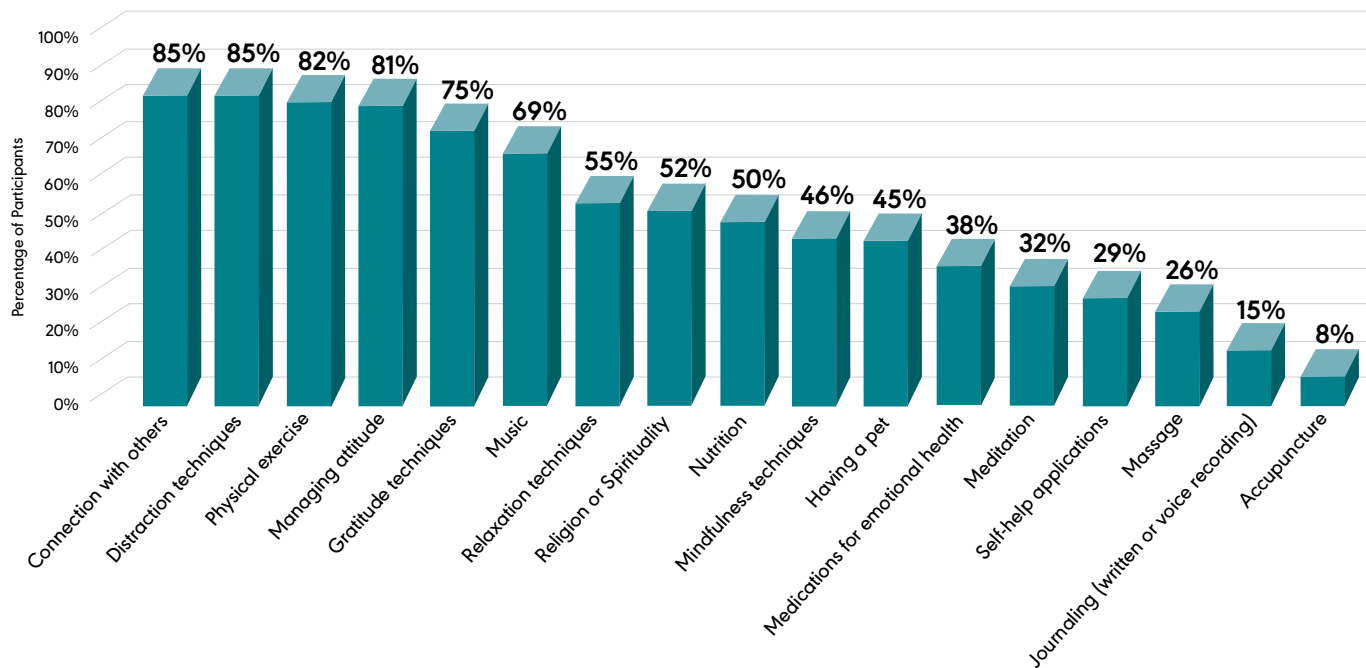


Figure 6: Coping Techniques for Emotional Health



SUMMARY AND DISCUSSION

Memory and emotional health are key elements to well-being and quality of life. While memory functions and emotional health are independent concepts in our day-to-day experiences, they are strongly related and can have a significant impact on our worldview and our function at home, in the community, and in the workplace.

TAKE HOME POINTS FROM THIS SURVEY:

Objective 1: To learn about the person with Parkinson's subjective report of memory difficulties and emotional health.

- As age increases, the vulnerability to experiencing memory difficulties also increases.
- While memory difficulties are expected to increase with disease duration, the **Younger PD Group** is particularly vulnerable to a noticeable increase to memory difficulties as disease duration increases beyond 6 years; a time period during which motor complications and increased use of medications is common.
- Memory difficulties did interfere with quality of life (QOL) for a large number of the participants.
 - Memory difficulties that interfered with quality of life increased as age and disease duration increased.
- Individuals experiencing depression and anxiety reported that memory difficulties interfere with QOL in higher frequency than those without emotional disturbance.

Objective 2: To understand the person with Parkinson's use of coping strategies in the context of memory and emotional disturbance.

- From the patient perspective, there is a lack of participation in thorough memory assessment and lack of education and treatment recommendations pertaining to memory treatment intervention.
- A relatively small portion of participants in this study reported clinical-provider facilitation of *non-medication*-based memory intervention (e.g., cognitive rehabilitation) and medication use for memory difficulties.
- The top 5 MEMORY coping techniques used by the participants in this study included keeping items in plain sight, using appointment books, making lists, using reminder notes, and creating a daily schedule.
- The top 5 EMOTIONAL coping techniques used by the participants in this study included connection with others, distraction, exercise, managing attitude, and gratitude statements.
- Engagement in coping strategies had a moderate to strong relationship with less emotional distress and better memory.

Objective 3: To provide general comments about and recommendations pertaining to memory functioning and emotional well-being.

- A formal assessment of memory and other cognitive functions (e.g., attention, higher level thinking skills—executive functioning) may be of benefit to identify what types of memory difficulties/cognitive difficulties are being experienced. Such understanding of symptoms will best guide the appropriate treatment plan.
 - Having a conversation with your Movement Disorder Specialist about appropriate assessments of cognition and mood is recommended (e.g., Neuropsychologists, Rehabilitation Specialists, such as Speech Language Pathologists, Occupational Therapists).
 - Participating in a neuropsychological assessment may be helpful in understanding the cognitive and psychological profile of individuals with PD, which can then guide treatment.
- A formal assessment of the contributing factors to memory difficulties may be of benefit, including the understanding of *possible reversible* causes of cognitive difficulties.
 - Talk to your doctor about treating symptoms that can impact cognitive functioning/mental efficiency, that, when treated successfully, may improve memory:
 - Sleep disturbance
 - Fatigue
 - Psychological factors (i.e., depression, anxiety, stress)
 - Pain
 - Malnutrition
 - Medications that adversely affect cognition.
- Cognitive-behavioral psychotherapy for individuals with PD that involves family or care providers (if appropriate) may help with adjustment to cognitive difficulties, psychosocial stressors, and related coping strategies.
- Medications for cognitive impairment may be helpful (e.g., cholinesterase inhibitors, such as Exelon). Talk to your doctor about the appropriateness and potential benefit of such medications.
- 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 foster cognitive engagement and purposeful living, which can have a favorable impact on physical, cognitive, and psychological well-being.

Memory Strategies/Cognitive Rehabilitation Strategies:

- Memory strategies for which training is given should be relevant to real life and should include memory training that are [real life] task or activity specific.
 - Think of memory strategies gaining compensatory techniques to aid in improving day-to-day functions.
 - Strategies should be practical (meaningful), simple in structure (minimizing frustration), and accessible.
- Consistent and routine application of strategies is recommended.
- When available, partnering with family members to help implement and reinforce memory compensatory strategies is recommended.
- Tailoring specific techniques to the individual's needs and capabilities is recommended. A treatment specialist can assist in creating a person-centered, intervention-based program to personal needs.

A commentary on the effectiveness of brain-training programs:

The greatest benefit of cognitive training/memory training programs relates to task-specific improvement with use of application of compensatory techniques²⁸. While there are several studies that laud the benefits of computerized brain-training programs, these studies tended to show relatively poor generalizability²⁹. Training improved performance on the specific task and those activities that were structurally similar to the task. Thus, learning compensatory strategies for task or activity specific can be helpful. As it relates to “brain games” using technology-based platforms, few studies provide any evidence that training with brain-training software or basic cognitive tasks yields improvements for cognitive performance in the real world.

Memory Techniques:

- **Memory difficulties for individuals with PD commonly relate to difficulties with:**
 - **Acquisition and Encoding** – The processes by which information (auditory and visual) or motor skills are initially organized and processed for either immediate repetition or later recall. These processes may be effortful or they may be out of conscious awareness.
 - **Retrieval** – The process by which previously learned information is recalled or brought into awareness. These processes may be effortful or passive.
- **Techniques that may be helpful in optimizing memory function:**
 - Minimize distractions in the environment.
 - Focus on one task at a time.
 - Maintain eye contact with others.
 - Repeat what was stated, especially when the information is important.
 - Ask questions to ensure the understanding of the content and context of the conversation.
 - Use external aids (cues), such as post-it notes or to-do lists.
 - Use alarm clocks, timers, other forms of technology to remind oneself of important tasks (e.g., when to take medication).
 - Use voice memos (e.g., in a smart phone) as an aid in remembering information.
 - Provide associations between things to be remembered in order to improve generalization of learning (e.g., notepad by the phone in order to take messages, basket by the door for keys).
 - Increase the relevance of presented information and decrease the amount of irrelevant information.

- **Sensory-specific Memory Skills Training** – specific strategies to improve memory can be developed based on the individual’s ability to recall information presented in different sensory modalities. Utilization of multiple sensory modalities is recommended.
 - Learning tasks or information by utilizing multiple sensory modalities (e.g., have the patient simultaneously see the material, hear the instructions, and perform the task).
 - Provide information in both verbal and visual modalities (e.g., provide a visual map, written instructions, and verbal instructions for travel).
 - Writing notes and reading them out loud (or listening to the notes).

- * **Treatment pertaining to memory functioning and general well-being in PD needs to be tailored to an individual’s preferences and capabilities. A one size fits all approach is not the best approach. For a review of a broad scope of PD symptoms and treatment considerations related to motor and non-motor symptoms, one can review previous survey reports on The Parkinson Alliance website that addresses a breadth of symptoms and treatment considerations.**
<https://www.parkinsonalliance.org/research-resources/patient-centered-research>

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Carol Walton
President and CEO
The Parkinson Alliance

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