



DBS4PD.org
an affiliate of The Parkinson Alliance

Improving the Quality of Life
in the Parkinson's Community

Patience:

The propensity of a person to wait calmly in the face of frustration, adversity, or suffering...enacted across a wide-range of circumstances and timeframes

Patience and Well-being in Parkinson's Disease

Fall 2015

INTRODUCTION

When confronted with a complex medical illness like Parkinson's disease (PD), debilitating symptoms, and/or daily stressors, patience may not be the first “coping mechanism” to come to mind. Patience is not traditionally thought of as a catalyst for improving well-being. In contrast, in today's era, it is more common to rely on medications for managing well-being or to try to find “quick fixes” to resolve a problem or to reduce discomfort. For example, our medical community commonly thinks about adding, tweaking, or changing medications in an attempt to improve symptom management. With burgeoning research on the practice of mindfulness, perspective management, and facilitation of positive thinking (i.e., expressing gratitude), it seems that there is greater appreciation for a holistic approach to medicine – improving well-being through a “well-being” model to compliment best medical therapy. Throughout history, patience has been upheld as an element of human strength and moral excellence, commended as a fundamental virtue and admirable character goal.¹ Patience has long been perceived as a character strength and desirable personality trait that promotes well-being. What is patience exactly? The concept of patience has been studied extensively by researcher Sarah Schnitker, PhD, who defined patience as “the propensity of a person to wait calmly in the face of frustration, adversity, or suffering ... enacted across a wide range of circumstances and timeframes.”² Patience can be conceptualized as both a disposition (how one holds himself or herself; a character trait) and state (i.e., emotional response; responding patiently to a situation).

Patience and General Well-Being

The practice of mindfulness has gained worldwide popularity as a method for emotional regulation and wellness maintenance. Among the basic tenets of mindfulness, patience has been identified as a key component.³ Schnitker's (2012) research indicated that patience serves as a buffer against emotions in stressful events, facilitates adaptive coping and higher self-esteem, and promotes positive interpersonal engagement, which can indirectly mediate goal achievement and satisfaction in life.²

Patience and Medical Conditions

There is limited research that examines patience in the context of medical conditions. Schnitker and Emmons (2007) indicated that there was an inverse relationship between patience and depression, while there was a positive relationship between impatience and self-reports of multiple negative health outcomes (i.e., headaches; ulcers).¹ Patience has not been directly studied in the context of PD.

OBJECTIVES

- To understand patience in the context of PD and clarify the relationship between patience and psychological well-being.
- To examine the relationship between patience and functional impairment on psychological outcome.

METHODS

- Participants were recruited from previous participants in surveys conducted by The Parkinson Alliance (PA), advertisements at PD support groups, announcements in medical clinics, The PA website, or a DBS-focused affiliate website to The PA (DBS4PD.org).
- There were 1,482 individuals who participated in this survey, including 408 participants with PD who underwent **DBS** and 1,073 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% of the surveys were completed independently, whereas, 15% of participants required writing assistance.
- Participants represented 50 states, with California (13%), Florida (11%), Arizona (10%), Texas (8%), New Jersey (8%), New York (8%), Colorado (6%), Pennsylvania (4%), Virginia (3%), and Michigan (2%) being the top 10 states that had the most participants. Geographical distribution was comparable between groups. There were 23 international participants.

Measures:

The Demographic Questionnaire and Questions Related to Patience and Psychological Well-being:

Questions related to demographic information/individual characteristics and patience and psychological well-being were included in this survey. Questions related to patience and psychological well-being included the following themes:

- The extent to which participants perceive themselves as patient individuals.
- The impact PD has on the participants' patience.
- The impact of patience on social engagements and relationships.
- Self-ratings of psychological well-being (i.e., depression, anxiety, frustration, stress), compassion and empathy.
- Self-rating of quality of life.

The 3-Factor Patience Questionnaire:² The self-report questionnaire has 11 items related to the patience in the following contexts:

- Interpersonal patience (Factor 1): 5 questions; i.e., I am patient with other people.
- Life hardship patience (long-term patience; Factor 2): 3 items; i.e., I find it pretty easy to be patient with a difficult life problem or illness; I am patient during life hardships.
- Daily hassles patience (short-term patience; Factor 3): 3 items; i.e., in general waiting in lines does not bother me.
- A Patience Composite Score: The sum of the following domains: Interpersonal patience, Life hardship patience, and Daily hassles patience.
 - The responses to the 11 questions included the following:
1 = Not like me at all; 2 = Unlike me; 3 = Neutral; 4 = Like me; 5 = Very much like me.
- Composure: Additional questions pertaining to “emotional composure” in the context of patience was also used in this study as a separate domain of patience (i.e., I consider myself as easy going; I am not easily irritated).
 - Responses to the 4 questions related to composure included:
1 = Not like me at all; 2 = Unlike me; 3 = Neutral; 4 = Like me; 5 = Very much like me.

Psychology Outcome Scale (self-report measure):⁴ This scale is comprised of 12 questions that make up three factors.

- Helplessness: 6 questions related to feeling perplexed and helpless, feeling out of control, and experiencing low self-esteem.
- Intrusion: 3 questions involving feeling resentful about their medical condition, asking “why me,” and feeling like the condition is an undeserved punishment.
- Personal Growth: 3 questions related to seeing personal growth resulting from their condition.

- The respondents rated each item on the following response scale:
1=Strongly Disagree; 2=Disagree; 3=Agree; 4=Strongly Agree.

Coping with Life Scale (self-report measure):⁵ This scale is comprised of 12 questions that make up 3 factors.

- Acceptance: 4 questions involving “acceptance” of their medical condition and re-evaluation of life values.
- Fighting Spirit: 5 questions involving determination and efforts to behave or function independently. The person tries to make the best of life despite the medical condition, tries to get along by her-/himself, and sets goals to achieve and attempts to find ways of adapting.
- Social Reliance: 3 questions related to the tendency to be dependent on others. Notably, the questions pertaining to Social Reliance were not included in this study.
 - The respondents rated each item on the following response scale:
1=Strongly Disagree; 2=Disagree; 3=Agree; 4=Strongly Agree.

Functional Status: The level of functional status was examined using a rating scale declaring to what extent an individual could perform basic and instrumental activities of daily living. Thirteen items were included in the scale, including: bathe yourself; maintain self-care; toileting/bowel & bladder; dress/clothe yourself; feeding yourself; preparing meals/cooking; shopping for groceries; doing the laundry/cleaning clothes; cleaning the house/home; managing your finances/pay bills; using the telephone; driving; managing medications. Response options included: *0=no difficulty; 1=minimal assistance; 2=moderate assistance; 3=major assistance; 4=unable to perform.*

Comparisons based on age and disease duration groups:

- The results will be presented using the entire sample (N=1,482) 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.^{6,7} 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.
- When considering the assessment tools used in this study,
 1. There may be additional questions pertaining to patience in PD that were not asked in this survey. Moreover, the questions in the patience questionnaire are general experiences that one may encounter, but may not be PD specific, thereby limiting understanding of patience in the context of PD symptoms.

- The Psychology Outcome Scale and The Coping with Life Scale address important psychological variables related to well-being in the context of medical illness, but additional questions may be helpful in understanding other facets of psychological well-being.

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 66 years)**. 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 (majority being married), race (majority being White/Caucasian), and education (majority having higher education) were comparable between groups.

Table 1. Demographics and Clinical Features of the Sample

	DBS (n =408)	Non-DBS (n =1,073)
Average Age in Years (range)*	66 (36-87)	71 (35-95)
Duration of PD in Years (range)*	15 (1-46)	7 (0-34)
Average Age of PD Diagnosis (range)*	52 (20-83)	64 (21-89)
Average Age at Time of DBS in Years (range)	61 (26-83)	n/a
Average Duration since DBS in Years (range)	5 (0-22)	n/a
Target: STN	54%	n/a
GPi	7%	n/a
Not Sure	39%	n/a
Male	60%	56%
Female	40%	44%
Married	78%	80%
Lives Alone	13%	14%
Race		
Caucasian	93%	95%
Latino/Hispanic	4%	2%
African American	<1%	<1%
Asian	1%	1%
American Indian	<1%	<1%
Other	<1%	<1%
Education		
<12 years	3%	4%
High School	10%	7%
Some College or Associate's Degree	23%	23%
College	25%	29%
Graduate/Advanced Degree	39%	37%

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

ATTITUDES ABOUT AND EXPERIENCES WITH PATIENCE (N=1,482):

- **When asked to what extent the participants perceive themselves as patient individuals:**
 - a) 52% of the participants perceive themselves as “quite a bit” to “extremely” patient.
 - b) 35% perceive themselves as “moderately” patient.
 - c) 13% perceive themselves as “not at all” to “a little bit” patient.
- **When asked to what extent PD has made the participants more patient:**
 - a) 27% of the participants believe that they are “quite a bit” to “extremely” more patient because of PD.
 - b) 25% indicated that they are “moderately” more patient because of PD.
 - c) 47% indicated that they are either “not at all” or only “a little bit” more patient because of PD.
- **When asked to what extent do participants believe patience helps them cope with/adjust to difficulties related to PD (i.e., difficulties with dressing, eating, walking, cleaning, getting in/out of a car, driving, working, etc.):**
 - a) 27% of the participants believe that they are “quite a bit” to “extremely” more patient because of PD.
 - b) 25% indicated that they are “moderately” more patient because of PD.
 - c) 47% indicated that they are either “not at all” or only “a little bit” more patient because of PD.
- **When asked to what extent does having patience increase their engagement in social activities:**
 - a) 34% reported that patience increased their engagement in social activities “quite a bit” or “extremely.”
 - b) 31% reported that patience increased their engagement in social activities “moderately.”
 - c) 35% indicated that patience did not have much impact on engagement in social activities (13% and 22% “not at all” and “a little bit,” respectively).
- **When asked to what extent do participants find that other people without PD are less patient with them:**
 - a) 15% perceive that others are “quite a bit” to “extremely” less patient with them.
 - b) 25% perceive that others are “moderately” less patient with them.
 - c) 60% either do not believe others are less patient with them or are “a little bit” less patient with them.

Patience and PD:

- The composite index on The Patience Questionnaire revealed that the majority of the participants perceive themselves as “likely to be patient” to “very likely to be patient” (see Table 2).
- When looking at patience in different contexts, such as interpersonal relationships, dealing with life hardships (i.e., patience with a difficult life problem or illness), and dealing with daily hassles (i.e., waiting in line), the majority of participants perceive themselves as patient (See Table 2).
- When asked about one’s ability to maintain emotional composure in the context of stress, the majority of individuals perceive themselves as not easily upset or irritated, and capable of accomplishing things without undue stress.

- Patience was comparable across age and disease duration. Moreover, there was not a statistically significant difference between age (**Younger** versus **Older**) and disease duration (**Early**, **Early Advanced**, and **Late Advanced**) groups as it related to patience (see Table 2).

Table 2. Patience and Domains of Patience: Across Age and Disease Duration Cohorts

Patience Questionnaire	Early PD Group (< 6 years duration)		Advanced PD Group			
	Younger (50-69) (n =241)	Older (70+) (n =255)	Younger (50-69) (n =173)	Older (70+) (n = 247)	Younger (50-69) (n =235)	Older (70+) (n =276)
Total Patience Composite Score						
Unlikely to be patient	16%	17%	17%	13%	14%	16%
Likely to be patient	62%	61%	54%	64%	58%	59%
Very Likely to be patient	22%	22%	29%	23%	28%	25%
Interpersonal Patience						
Unlikely to be patient	17%	18%	20%	17%	17%	19%
Likely to be patient	55%	60%	53%	61%	55%	56%
Very Likely to be patient	28%	22%	27%	22%	28%	25%
Long-term Patience (Dealing with life hardships)						
Unlikely to be patient	22%	25%	24%	22%	28%	27%
Likely to be patient	60%	60%	56%	59%	53%	56%
Very Likely to be patient	18%	15%	20%	19%	19%	17%
Short-term Patience (Dealing with daily hassles)						
Unlikely to be patient	31%	30%	28%	30%	25%	26%
Likely to be patient	51%	48%	43%	44%	46%	49%
Very Likely to be patient	18%	22%	29%	26%	29%	25%
Maintaining Composure (Emotional control in the context of patience)						
Unlikely to be patient	9%	9%	4%	4%	6%	4%
Likely to be patient	72%	68%	76%	73%	70%	73%
Very Likely to be patient	19%	23%	20%	23%	24%	23%

PSYCHOLOGICAL WELL-BEING AND PD

Participants were asked to rank their levels of frustration, depression, anxiety, compassion, and empathy using a scale from 0-10, with 0-3=*mild/a little*, 4-7=*moderate*, 8-10=*severely/extremely* (see Table 3).

- High rates of emotional discomfort were reported by participants (See Table 3).
- The vast majority of individuals perceive themselves as compassionate and empathetic.

Table 3. Emotional Well-being	
Psychological Construct	Percentage
Stress	
None to Mild/“A Little”	58%
Moderate	30%
Severely/Extremely	12%
Frustration (Over the past two weeks)	
None to Mild/“A Little”	45%
Moderate	47%
Severely/Extremely	8%
Depression (Over the past two weeks)	
None to Mild/“A Little”	63%
Moderate	31%
Severely/Extremely	6%
Anxiety (Over the past two weeks)	
None to Mild/“A Little”	53%
Moderate	37%
Severely/Extremely	10%
Compassionate	
None to Mild/“A Little”	8%
Moderate	47%
Extremely	45%
Empathetic	
None to Mild/“A Little”	10%
Moderate	47%
Extremely	43%

When looking at core features of coping and psychological well-being (see Table 4), the vast majority of individuals perceive themselves as:

1. Accepting of their medical condition (i.e., I think I have accepted my medical condition; I have learned to appreciate new aspects of life that I did not think about before.).
 2. Finding personal growth in the context of their medical condition (i.e., I have greater perspective on life due to my medical condition.).
 3. Having a fighting spirit (i.e., I try to make the best of life despite my condition; I try to find tricks that might make my situation less difficult.).
- Unlike patience, the psychological variables “acceptance,” “personal growth,” and “fighting spirit” appear to be more vulnerable to change with age and level of functional difficulty. Specifically, **Younger** PD participants (age 50-69) had greater reports of personal growth, acceptance, and fighting spirit, and lower impairment/dependency scores than **Older** participants (age 70+).
 - Consistent with the elevated levels of psychological discomfort (i.e., stress, frustration, anxiety, and depression), a large percentage of participants engage in maladaptive or negative self-talk (i.e., I often ask why this happened to me; My medical condition feels like an undeserved punishment.).
 - Negative self-talk is generally consistent, and is commonly experienced, across age and disease duration (see Table 4).
 - Additionally, a large percentage of participants perceive themselves as feeling helpless (i.e., I often feel at a loss without knowing what to do; It often feels like I have no control over my life; Sometimes I feel ashamed of my condition.).
 - Helplessness is generally consistent, and is commonly experienced, across age and disease duration (see Table 4).
 - There was a significant relationship between negative self-talk (i.e., negative intrusive thoughts) and helplessness and emotional distress; the greater the negative self-talk and/or helplessness, the higher the greater the report of emotional disturbance.

Table 4. Facets of Psychological Well-being: Across Age and Disease Duration Cohorts

	Early PD Group (< 6 years duration)		Advanced PD Group			
			6-10 years duration		11+ years duration	
Patience Questionnaire	Younger (50-69) (n =232)	Older (70+) (n =255)	Younger (50-69) (n =173)	Older (70+) (n = 247)	Younger (50-69) (n =235)	Older (70+) (n =276)
Personal Growth Resulting from PD						
Strongly Disagree/Disagree	23%	32%	18%	35%	19%	31%
Agree/Strongly Agree	77%	68%	82%	65%	81%	69%
Acceptance of PD						
Strongly Disagree/Disagree	17%	18%	14%	17%	16%	17%
Agree/Strongly Agree	83%	72%	86%	83%	84%	83%
Fighting Spirit						
Strongly Disagree/Disagree	3%	3%	2%	6%	6%	4%
Agree/Strongly Agree	97%	97%	98%	94%	94%	96%
Feelings of Helplessness						
Strongly Disagree/Disagree	62%	56%	65%	67%	70%	67%
Agree/Strongly Agree	38%	44%	35%	33%	30%	33%
Experience Intrusive Thoughts (That lead to negative feelings)						
Strongly Disagree/Disagree	33%	28%	32%	30%	29%	33%
Agree/Strongly Agree	67%	72%	68%	70%	71%	67%

THE RELATIONSHIPS BETWEEN PSYCHOLOGICAL WELL-BEING AND PATIENCE:

- Patience was significantly related to psychological well-being and quality of life.
 - The greater one reported being patient, the greater the report of psychological well-being (lower levels of frustration, stress, depression, and anxiety), and the greater one's psychological well-being the more patience was reported.
- There was a positive relationship between patience and compassion and empathy.
- There was a positive relationship between patience and quality of life.

RELATIONSHIP BETWEEN FUNCTIONAL DIFFICULTY AND PATIENCE AND PSYCHOLOGICAL WELL-BEING

- Patience did not have a strong relationship with the level of functional difficulty one experiences.
 - Patience appears to be more of a "trait" (a distinguishing feature of a person; part of one's character) than a state (a specific condition that someone is in at a specific time).

- Functional difficulty had a significant relationship with psychological well-being.
 - The greater the functional difficulty, the worse the rating of psychological well-being (i.e., helplessness, intrusive thoughts, depression, anxiety, stress, frustration).
- Functional difficulty had a significant relationship with quality of life, in that the greater the functional difficulty, the worse the rating of quality of life.

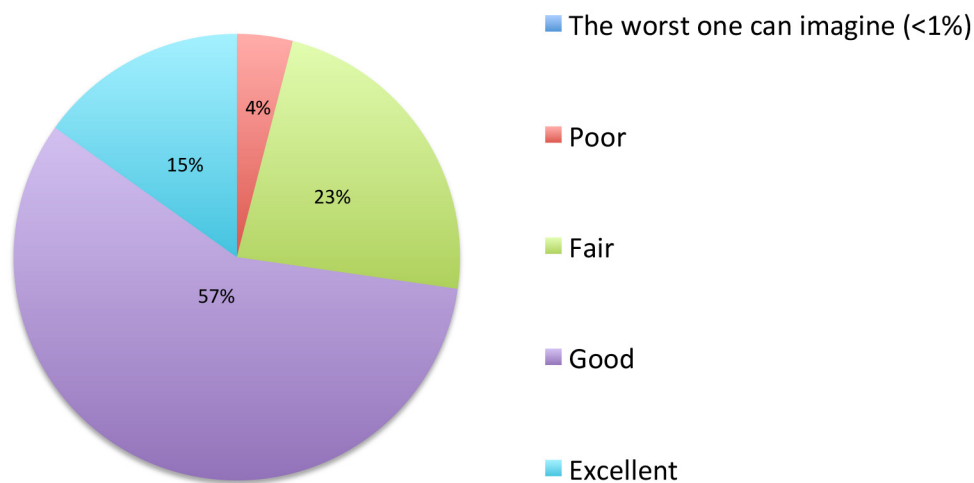
DBS VERSUS NON-DBS PARTICIPANTS AS IT RELATES TO PATIENCE:

- There was not a significant difference in “patience” (on any subdomain) between the **DBS group** and the **Non-DBS group**.

QUALITY OF LIFE (Figure 1):

- The majority of participants perceive their overall quality of life as good to excellent.
- <1 percent perceive their quality of life as “the worst one can imagine”

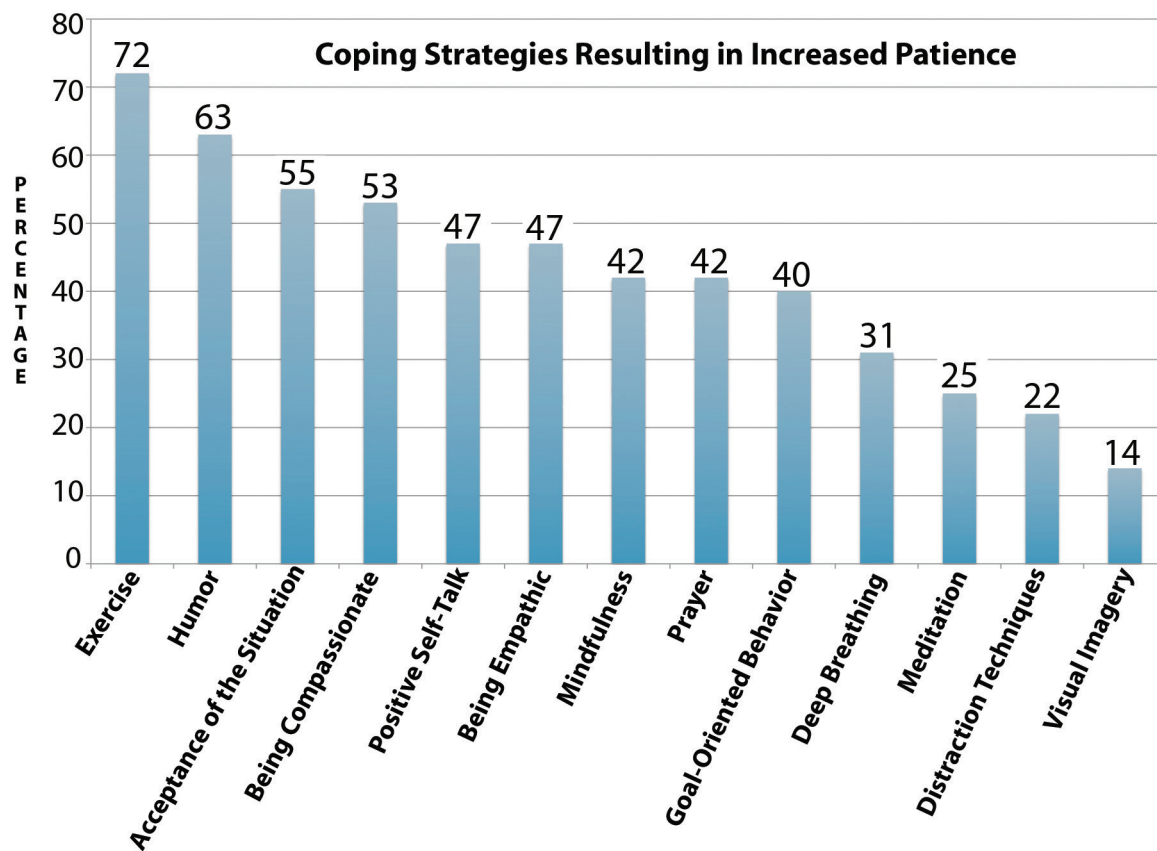
Figure 1. Quality of Life Ratings



COPING STRATEGIES THAT HAVE RESULTED IN INCREASED PATIENCE (see Figure 2):

- The number one coping technique reported to increase patience was exercise, followed by humor, acceptance of the situation, and being compassionate, all of which were reported as coping techniques used by more than 50% of the participants.
- 40 to 47% of the participants reported that use of positive self-talk, being empathetic, mindfulness, prayer, and goal-oriented coping has resulted in increased patience.
- Less frequently used techniques to increase patience included deep breathing, meditation, distraction techniques, and visual imagery.

Figure 2. Coping Strategies Resulted in Increased Patience (N=1,482)



SUMMARY AND DISCUSSION

TAKE HOME POINTS FROM THIS SURVEY:

- The majority of the participants in this survey perceive themselves as “patient.”
- About half of the participants believe that PD has made them more patient.
- The majority of participants believe that having patience helps them cope with PD.
- Over half of the participants reported that patience increased their engagement in social activities.
- 40% of the individuals with PD have found others without PD to be less patient with them.
- Patience has a significant relationship with psychological well-being and quality of life.
 - Research supports the notion that patience can be a buffer against emotions in stressful situations, allows the person to cope more adaptively with frustrations, facilitates positive interpersonal interactions, and facilitates goal attainment.²
- Patience was not significantly different across age and disease duration groups. And, patience was not significantly related to functional difficulties.
 - Patience appears to be more of a “trait” (a distinguishing feature of a person; part of one’s character) than a state (a specific condition that someone is in at a specific time).
- Unlike patience, the psychological variables “acceptance,” “personal growth,” and “fighting spirit” appear to be more vulnerable to change with age and/or level of functional difficulty. Specifically, Younger PD participants (age 50-69) had greater reports of personal growth, acceptance, and fighting spirit than Older participants (age 70+).
- There was a significantly high number of participants with emotional distress/discomfort, and a large number of participants reported engaging in maladaptive/negative thoughts.
 - It is well-known that negative self-talk and feelings of helplessness have been linked to poor coping and increased psychological distress.
 - Regardless of age and disease duration, negative thoughts pertaining to their well-being are prevalent.
- Patience is an important variable that has significant relationship with perceived well-being. That said, psychological well-being is multi-faceted and complex, and patience is just one spoke in the big wheel.
- The number one coping technique reported to increase patience was exercise, followed by humor, acceptance of the situation, and being compassionate, all of which were reported as coping techniques used by more than 50% of the participants.
 - There are numerous adaptive coping mechanisms that may contribute to patience, however, that are unknown, unfamiliar or underutilized by individuals.

GENERAL IMPLICATIONS AND RECOMMENDATIONS:

There are numerous symptoms within the motor and non-motor domains and additional life stressors that can challenge psychological well-being for individuals with PD. Intervention in managing symptoms and general well-being commonly defaults to the medical model – attempts to pursue quick fixes and initiate or change medications to address symptoms. It is also worth noting that symptoms of PD can adversely impact emotional well-being for those who share their lives with individuals with PD. For example, the commonly seen “masked face” can lead to misinterpretation or misunderstanding

of what individuals with PD may be experiencing and may lead to frustration and/or stress. Additionally, difficulties with cognitive functions/thinking skills, changes in behavior (i.e., reduced initiation, increased apathy, etc.), and/or difficulties with speech expression (i.e., slurred speech, low volume, etc.) can also lead to increased stress and diminished frustration tolerance.

In today's era, a more holistic approach to well-being to address a broader scope of wellness for people with PD and family and/or carers is being proposed. Three facets of the "well-being model" rather than the "symptom-focused model" include mindfulness (of which "patience" is a part), perspective management, and behavioral activation.

- Given research on patience (and mindfulness) and anecdotal evidence through conversations abound, integrating patience into daily situations and encounters with others can have a favorable impact on how one experiences "the moment."
- Increasing awareness and application of techniques related to patience and mindfulness may increase psychological well-being, facilitate goal attainment, and improve quality of life.^{1,2}
 - Mindfulness means maintaining a moment-by-moment awareness of our thoughts, emotions, bodily sensations, and surrounding environment. Mindfulness training incorporates a set of techniques and methods for systematically developing a present-centered focus and a heightened sense of awareness. The practice of mindful awareness has a variety of well-documented impacts, including a reduction in toxic stress, an increase in emotion regulation, and an improvement in cognitive function.⁸
 - Resources on mindfulness can be found online and in bookstores, and commonly within the scope of mental health services (i.e., mental health professionals, community resources).
- Psychological well-being, above and beyond implementing patience, is important to address. Perspective management and behavioral activation are key features to a wellness model.
 - Perspective Management: The way individuals think about or "appraise" their medical condition and the coping strategies they use in response to these appraisals have a significant role in the process of adjustment and facing challenges.
 - Learning strategies to manage attitude and thoughts/interpretations (i.e., controlling our self-talk and engaging in adaptive interpretations of situations) is a key element in improving psychological well-being.
 - Behavioral Activation: As found in this survey and in our previous survey on "Exercise," exercise (behavioral activation) is a key element to improving health and psychological well-being.⁹ Goal-oriented behaviors in general can improve well-being.¹⁰
 - Positive Psychology promotes a "well-being" approach rather than "symptom focus" approach.¹⁰
 - Experiencing positive emotion (pleasant experiences), engagement (getting absorbed by a task), relationships (connecting with others), meaning and purpose, and achievement-oriented behaviors have been found to help to facilitate better well-being. Moreover, when one is truly engaged in pleasant experiences within these domains, it is more challenging to focus on "symptoms."
 - The focus of our attention can directly impact our emotional well-being. It can be helpful to think about the phrase, "Where the attention goes the emotion flows," which can serve as a reminder to focus on pleasant and meaningful words, experiences, interactions, events, etc.

- Expressing gratitude, experiencing humor, and engaging in acts of kindness are also mechanisms for “feeling better” in the moment.
- Using resources in the community, such as support groups, rehabilitation teams, mental health professionals, exercise groups, and the like, can help individuals participate in activities that will help foster perspective management and behavioral activation.

ACKNOWLEDGEMENTS

In this 19th survey, we continue to have excellent participation in our surveys. I want to express my deep appreciation to all those who participated in this study and to the many carers without whom our lives would not be as meaningful. Notably, it takes a team to conduct these research endeavors. I want to extend my appreciation to Jeffrey Wertheimer, Ph.D., ABPP-CN, our Chief Research Consultant and Head of Neuropsychology Services at Cedars-Sinai Medical Center, Los Angeles, California, who assists in creating the research surveys, analyzing the data, and writing our manuscripts. I want to thank Miriam Nuno, Ph.D., a Biostatistician in the Department of Neurosurgery at Cedars-Sinai Medical Center, for her assistance with data analysis. Thanks goes to Ann Gottuso, Ph.D., neuropsychology fellow, and Justin Miller, MA, neuropsychology student, at Cedars-Sinai Medical Center, Los Angeles, CA, for preparation and review of the manuscript. Additionally, I want to thank Aurore Duboille, DBS Survey Coordinator, for her assistance with database management, Gloria Hansen, Graphic Designer for The Parkinson Alliance, and Carol Walton, Chief Executive Officer for The Parkinson Alliance, who assist at many levels in making this research possible.

Margaret Tuchman,
Bilateral DBS-STN, 2000
President, The Parkinson Alliance

References

1. Schnitker, S. A., & Emmons, R. A. (2007). Patience as a virtue: Religious and psychological perspectives. *Research in the Social Scientific Study of Religion, 18*, 177-207. doi: 10.1163/ej.9789004158511.i-301.69
2. Schnitker, S. A. (2012). An examination of patience and well-being. *Journal of Positive Psychology, 7*, 263-280. doi:10.1080/17439760.2012.697185
3. Kabat-Zinn, J. (2001). *Mindfulness meditation for everyday life*. London, England: Piatkus Books.
4. Elfstrom, M.L., Kreuter, M., Ryden, A., Person, L-O, & Sullivan, M. (2002). Effects of coping on psychological outcome when controlling background variables: a study of traumatically spinal cord lesioned persons. *Spinal Cord, 40*, 408-415.
5. Elfstrom, M.L., Kennedy, P., Lude, P., & Taylor, N. (2007). Condition-related coping strategies in persons with spinal cord lesion: a cross-national validation of the Spinal Cord Lesion-Related Coping Strategies Questionnaire in four community samples. *Spinal Cord, 45*, 420-428.
6. Politis, M., Wu, K., Molloy, S., G Bain, P., Chaudhuri, K., & Piccini, P. (2010). Parkinson's disease symptoms: the patient's perspective. *Movement Disorders, 25*(11), 1646-1651.
7. Shrag, A. & Quinn, N. (2000). Dyskinesias and motor fluctuations in Parkinson's disease. A community-based study. *Brain, 123*(11), 2297-305.
8. Prakash, R.S., Hussain, M.A., & Schirda, B. (2015). The role of emotion regulation and cognitive control in the association between mindfulness disposition and stress. *Psychology Aging, 30*(1), 160-171.
9. Wertheimer, J., Ellis, T., Nuno, M., Duboille, A., Walton, C., Gottuso, A., Tuchman, M. (2015). Exercise in Parkinson's disease with and without deep brain stimulation: a closer look from the patient's perspective. The Parkinson Alliance Website, DBS4PD.org: http://www.dbs4pd.org/media/file/DBS_ExerciseReport_Spring2015_final.pdf.
10. Seligman, M.E.P. (2011). *Flourish: a visionary new understanding of happiness and well-being*. New York, NY: Free Press.

DBS4PD.org

an affiliate of The Parkinson Alliance

Post Office Box 308 • Kingston, New Jersey 08528-0308
Phone: 1-800-579-8440 or (609) 688-0870 • Fax: (609) 688-0875

www.parkinsonalliance.org
a 501(c)(3) non-profit corporation