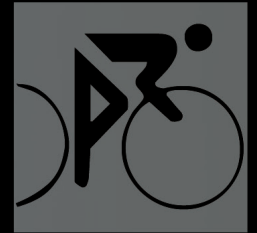




DBS4PD.org

an affiliate of The Parkinson Alliance

Improving the Quality of Life
in the Parkinson's Community



Exercise & Parkinson's Disease with and without DBS:

A Closer Look from the Patient's Perspective

Spring 2015

Introduction

The concept that exercise is an important part of maintaining good health, for both mind and body, is far from novel. Even Plato around 400 BC stated, “Lack of activity destroys the good condition of every human, while movement and methodical physical exercise save and preserve it”¹. In recent years, there has been a surge of research exploring factors related to exercise and Parkinson’s disease (PD). Animal models have found that exercise triggered plasticity-related changes in the central nervous system^{2,3}. Giselle Petzinger, Beth Fisher, and colleagues at the University of Southern California in Los Angeles looked at exercise in humans with PD and found that high-intensity exercise resulted in symptomatic improvement^{2,4}. Furthermore, exercise has been found to decrease disability and improve quality of life in people with PD^{5,6}.

As we look closer into the details related to research and exercise for individuals with PD, studies have revealed that gait, balance, strength, flexibility, and cardiovascular fitness improve in people who have PD and exercise⁷⁻¹⁴. There have been studies investigating the impact of specific types of exercise and symptoms of PD. Aerobic exercise, for example, such as brisk walking in the community or on a treadmill^{12, 15}, dancing¹⁶, and cycling^{17, 18} has been found to improve physical function (i.e., balance, gait, slowness of movement), brain health¹⁹, and quality of life⁵. Higher intensity exercise for individuals with PD (i.e., involving resistance training) has been found to have favorable results on gait^{20, 21}. Other forms of exercise, such as Tai Chi, have been found to help balance issues^{22, 10}. Furthermore, Murray and colleagues²³ conducted a review of clinical studies that showed that various types of exercise, such as aerobic, resistance, and dance, can improve cognitive function in individuals with PD.

Deep brain stimulation (DBS) has been found to be an effective therapy for improving motor symptoms related to PD and even some non-motor symptoms^{24, 25}. Although improvements in motor symptoms have been reported to result in improved motor function and quality of life, some research has found that DBS has not increased physical activity. For example, Deneault and colleagues²⁶ concluded that while there are motor improvements observed after STN-DBS, such improvements do not necessarily lead to increased levels of physical activity. Another study found that despite significant improvements in motor symptoms after DBS surgery, the volume of walking activity (total number of steps per day) did not change²⁷. More specifically, walking mechanics did improve, such that significant increases in length and variability of walking bouts emerged, suggesting improvements in diversity and flexibility of walking patterns. Walking activity, however, did not increase.

Although most people with PD believe that exercise is important, there may be many barriers that limit participation in exercise. For example, low outcome expectation from exercise, reduced confidence in ability to exercise successfully, lack of time to exercise, and fear of falling appear to be important perceived barriers to engaging in exercise in people who have PD^{28, 29}. Thus, although much knowledge about the benefits of exercise in improving PD symptoms, reducing disability, and improving quality of life and general well-being has been established, there remains a gap in our knowledge about the experience of and perception about exercise from the patient’s perspective, particularly in the context of age and disease duration.

Objective

To obtain a better understanding about attitudes and knowledge about exercise, current level of exercise, benefits of exercise, and barriers to exercise from the perspective of individuals with PD, particularly in the context of age and disease duration cohorts.

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 the DBS-focused affiliate website to The PA (DBS4PD.org).
- There were 1,500 individuals who participated in this survey, including 394 participants with PD who underwent **DBS** and 1,106 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, approximately 13% of participants required writing assistance.
- Participants represented 50 states, with California (15%), Arizona (12%), Florida (11%), Texas (10%), New Jersey (9%), New York (7%), Colorado (5%), Pennsylvania (5%), Virginia (3%), and Michigan (2%) being the top 10 states that had the most participants. Geographical distribution was comparable between groups. There were 22 international participants.

Measures:

The Demographic Questionnaire and Questions Related to Exercise:

Questions related to demographic information/individual characteristics and exercise were included in this survey. Questions related to exercise include:

- Attitudes and Knowledge Regarding Exercise
- Current Level of Exercise
- Perceived Benefits of Exercise
- Perceived Barriers to Exercise
- Technology and Exercise
- Exercise as it relates to comparing DBS and Non-DBS groups

Comparisons based on age and disease duration groups:

- The results will be presented using the entire sample (N=1,500) 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^{30, 31}. 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, DBS, Non-DBS etc.), since some individuals may not have responded to a specific question.

Results

The summary of the demographic information for 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 (**51 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=394)	Non-DBS (n=1106)
Average Age in Years (range)*	66 (38-87)	71 (40-95)
Duration of PD in Years (range)*	15 (1-46)	7 (0-49)
Average Age of PD Diagnosis (range)*	51 (20-78)	64 (20-90)
Average Age at Time of DBS in Years (range)	61 (26-85)	n/a
Average Duration since DBS in Years (range)	5 (0-25)	n/a
Bilateral Stimulation	87%	n/a
Target: STN	58%	n/a
GPI	8%	n/a
Thalamus	1%	n/a
Not Sure	33%	n/a
Male	59%	57%
Female	41%	43%
Married	77%	79%
Lives Alone	13%	15%
Race		
Caucasian	96%	94%
Latino/Hispanic	2%	3%
African American	<1%	1%
Asian	1%	1%
American Indian	<1%	<1%
Other	<1%	<1%
Education		
<12 years	4%	3%
High School	10%	9%
Some College or Associate's Degree	24%	22%
College	24%	29%
Graduate/Advanced Degree	38%	37%
*Clinically significant difference between groups n/a = not applicable		

ATTITUDES AND KNOWLEDGE REGARDING EXERCISE (N=1,500):

- The majority of participants (59%) in this survey indicated that they engaged in exercise on a fairly regular or regular basis during their adulthood.
 - 22% exercised regularly throughout life
 - 37% exercised fairly regularly much of the time
 - 29% exercised occasionally
 - 12% never exercised regularly
- Only a small portion (16%) of individuals reported that their parents were involved in exercise.
- 84% of the participants reported that their Parkinson's doctor has recommended that they exercise.
- 66% of the participants reported that their Parkinson's doctor has recommended Physical Therapy.
 - 62% of the participants reported that they have participated in Physical Therapy for treatment of their PD.
- The vast majority of the participants reported that exercise is “quite a bit” to “extremely” important (87%), with 10% indicating that exercise is “moderately” important and less than 3% indicating that exercise is “not at all” important to “a little bit” important.
- In response to how often the participants believe a person with PD needs to exercise:
 - 86% of the participants reported that an individual with PD should exercise 3 times per week or more.
 - 8% believe that an individual with PD should exercise once or twice per week.
 - <1% believe that an individual with PD should exercise once or twice per month.
 - 1% believe that an individual with PD should not exercise.
 - 4% did not know how much an individual with PD should exercise.
- In response to how long a person with Parkinson's should exercise per session:
 - 40% of the participants reported that an individual with PD should exercise for 45 minutes or more.
 - 46% believe that an individual with PD should exercise for approximately 30 minutes.
 - 5% believe that an individual with PD should exercise 15 minutes or less.
 - 2% believe that an individual with PD should not exercise.
 - 7% did not know how long an individual with PD should exercise.
- As for life satisfaction:
 - 9% indicated that they were “extremely satisfied”
 - 35% indicated that they were “very satisfied”
 - 40% indicated that they were “somewhat satisfied”
 - 11% indicated that they were “only a little satisfied”
 - 5% indicated that they were “not at all satisfied”

Note: There was relatively slight decrement in life satisfaction as age and disease duration increase (see Table 2).

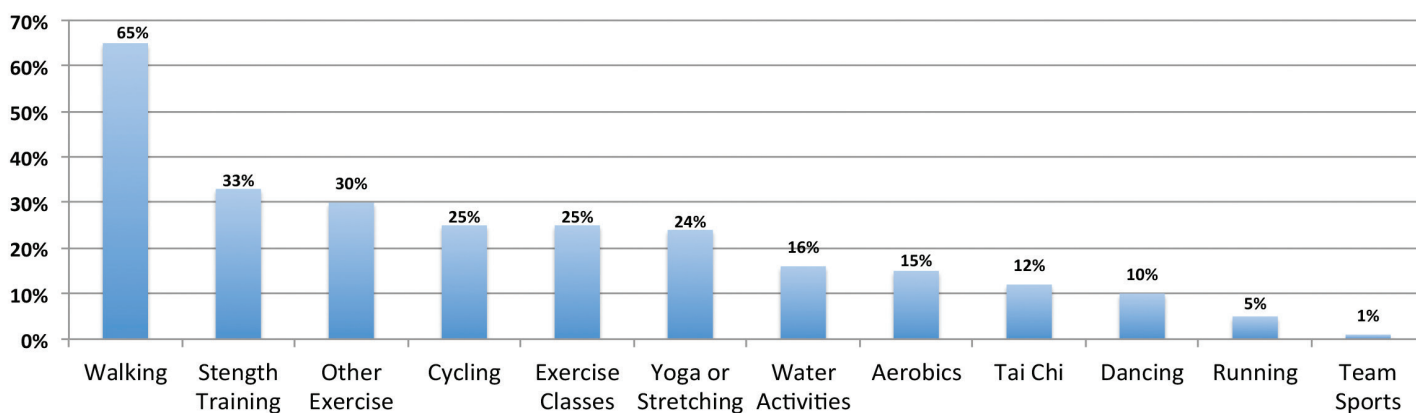
Table 2: Life Satisfaction: Across Age and Disease Duration Cohorts

Life Satisfaction	Early PD Group (< 6 years duration)		Advanced PD Group			
	Younger (50-69 years) (n =231)	Older (70+ years) (n =299)	6-10 years duration		11+ years duration	
			Younger (50-69 years) (n =161)	Older (70+ years) (n = 246)	Younger (50-69 years) (n =237)	Older (70+ years) (n =274)
Not at All Satisfied	2%	8%	3%	3%	5%	10%
Only a Little Satisfied	5%	7%	14%	14%	14%	13%
Somewhat Satisfied	42%	38%	39%	42%	39%	39%
Very Satisfied	36%	38%	34%	34%	35%	30%
Extremely Satisfied	14%	9%	11%	7%	7%	8%
Don't Know	<1%	1%	0%	0%	<1%	1%

CURRENT LEVEL OF EXERCISE:

- 125 out of 1,500 participants reported that they do not participate in exercise at the time of this survey.
- Individuals who participated in this survey engage in a variety of exercise activities. Walking was the most commonly reported exercise activity followed by strength training/weight lifting. Figure 1 provides a list of exercise activities in which the respondents are currently participating.

Figure 1. Current Exercise Activities (N=1,500)



- In Figure 1, “Other exercise” includes, for example, Pilates, Nautilus (which may be considered as strength training for some), tennis, boxing, rowing, golf, PD Boot Camp (which may be considered an exercise class for some), chair exercises, among others.
- As can be seen in Table 3, the majority of participants engage in some level of exercise weekly to increase muscle strength, balance, flexibility, and/or aerobic fitness across age and disease duration cohorts.
- As PD duration increases and as individuals get older, walking duration decreases (See Table 3).
- Approximately 90% of the participants remain sedentary for more than 2 hours a day (regardless of age and disease duration; see Table 3). 45 to 57% of the participants in this survey (depending on age and disease duration) reported that they remain sedentary for more than 5 hours per day.

Table 3: Participants Reporting Level of Exercise: Across Age and Disease Duration Cohorts

Level of Exercise	Early PD Group (< 6 years duration)		Advanced PD Group			
	Younger (50-69) (n =231)	Older (70+) (n =299)	6-10 years duration		11+ years duration	
	Younger (50-69) (n =161)	Older (70+) (n = 246)	Younger (50-69) (n =237)	Older (70+) (n =274)		
Use exercise to increase MUSCLE STRENGTH/TONE						
Not at all	23%	31%	34%	39%	30%	41%
Less than twice a month	12%	17%	15%	19%	21%	16%
1-2 days per week	32%	26%	26%	23%	27%	20%
3-7 days per week	33%	26%	24%	20%	21%	22%
Use exercise to increase BALANCE						
Not at all	26%	29%	35%	34%	35%	39%
Less than twice a month	16%	15%	17%	15%	18%	23%
1-2 days per week	32%	33%	26%	28%	27%	24%
3-7 days per week	26%	23%	21%	24%	21%	25%
Use exercise to increase FLEXIBILITY						
Not at all	21%	29%	29%	26%	31%	30%
Less than once a month	5%	2%	8%	4%	8%	7%
Once or twice a month	6%	6%	8%	9%	9%	10%
1-2 days per week	29%	30%	26%	26%	26%	26%
3-5 days per week	29%	27%	22%	27%	21%	22%
6-7 days per week	11%	6%	8%	7%	5%	6%
Use exercise to increase AEROBIC FITNESS						
Not at all	28%	46%	34%	53%	33%	56%
Less than twice a month	17%	12%	15%	15%	18%	13%
1-2 days per week	24%	18%	24%	14%	22%	15%
3-7 days per week	32%	24%	28%	18%	26%	16%
LENGTH of the EXERCISE SESSION						
Not applicable	10%	8%	14%	11%	9%	14%
15 minutes or less	10%	13%	12%	18%	14%	23%
Approx. 30 minutes	31%	32%	32%	29%	36%	36%
More than 45 minutes	48%	46%	41%	41%	39%	26%
Don't know	1%	0%	1%	2%	1%	1%

Table 3 cont.	Early PD Group (< 6 years duration)		Advanced PD Group			
			6-10 years duration		11+ years duration	
Level of Exercise	Younger (50-69) (n =231)	Older (70+) (n =299)	Younger (50-69) (n =161)	Older (70+) (n = 246)	Younger (50-69) (n =237)	Older (70+) (n =274)
Walk for at least 30 consecutive minutes						
Not at all	22%	36%	28%	36%	24%	52%
Less than twice a month	7%	18%	23%	24%	32%	21%
1-2 days per week	21%	18%	21%	18%	20%	13%
3-7 days per week	41%	29%	28%	22%	24%	24%
Hours of SEDENTARY activities						
None	4%	3%	2%	3%	2%	3%
Less than 2 hours	7%	7%	10%	8%	10%	7%
2-4 hours	37%	45%	40%	39%	37%	32%
5-7 hours	35%	31%	32%	30%	32%	37%
More than 7 hours	17%	14%	17%	20%	19%	20%

BENEFITS OF EXERCISE:

- The top five MOST frequently reported “MAJOR” reasons to exercise across age and disease duration groups in order of greatest to least included:
 - Improving health (86-92% of the participants)
 - Slowing the progress of PD (74-92%)
 - Maintaining independence (75-85%)
 - Increasing fitness level (71-80%)
 - Increasing energy level (67-78%)
- “MAJOR” reasons to exercise that were reported in MODERATE frequency included:
 - Feeling good about self (54-72%)
 - Feeling in control of life (51-61%)
 - Reducing stress (43-60%)
 - Fighting aging (44-55%)
 - Controlling weight (35-54%)
- The following 3 “MAJOR” reasons to exercise were the LEAST frequently reported:
 - Looking good (36-49%)
 - Having fun (33-44%)
 - Socializing with others (27-39%)

BARRIERS TO EXERCISE:

- The top five MOST frequently reported BARRIERS to exercise across age and disease duration groups in order of greatest to least (on average) included:
 - Too fatigued or tired (61-74% of the participants)
 - Health problems related to PD (46-67%)
 - Health problems not related to PD (50-60%)
 - Pain when exercising (42-57%)
 - Fear of falling/getting hurt (35-64%)

- BARRIERS to exercise that were reported in MODERATE frequency included:
 - Exercise is boring or not enjoyable (34-40%)
 - Not motivated to exercise (30-42%)
 - Not sure what exercise to do (21-36%)
 - Self-conscious (17-39%)
 - Don't have enough time (23-30%)

- The 5 BARRIERS to exercise that were the LEAST frequently reported included:
 - No one to exercise with (17-37%)
 - Gym memberships are too expensive (17-37%)
 - Not sure if exercising will make a difference (13-36%)
 - Access (8-23%)
 - No place to exercise (8-19%)

Note: Barriers tended to increase in frequency with increased age and increased duration of PD.

PD-RELATED BARRIERS (see Table 4):

- Age and disease duration have an adverse impact on engagement in exercise. Moreover, the extent to which PD prevents participants from exercising increases significantly as disease duration increases, in both younger and older cohorts. Despite the increasing interference from PD symptoms on exercising, the majority of participants in this survey continue to engage in exercise.

- As it relates to common motor and non-motor symptoms of PD, the greatest barriers to exercise include balance problems, walking difficulties, and stiffness. Other commonly reported motor symptoms that are barriers to exercise include: dystonia, dyskinesia, and tremor.

- Of the non-motor symptoms included in this survey (cognitive difficulties, anxiety, stress, depression, and apathy), cognitive difficulty was the most frequently reported non-motor (on average) barrier to exercise.

Table 4: Participants Reporting PD-Related Barriers: Across Age and Disease Duration Cohorts

PD Related Barriers to Exercise	Early PD Group (< 6 years duration)		Advanced PD Group			
	Younger (50-69) ($n = 231$)	Older (70+) ($n = 299$)	6-10 years duration		11+ years duration	
			Younger (50-69) ($n = 161$)	Older (70+) ($n = 246$)	Younger (50-69) ($n = 237$)	Older (70+) ($n = 274$)
Extent PD prevents from Exercising						
Not at all	32%	34%	19%	20%	12%	16%
A little bit	35%	31%	30%	23%	28%	23%
Moderately/Quite a bit	32%	34%	49%	56%	59%	59%
Completely	1%	1%	2%	1%	1%	2%
Tremor	23%	20%	30%	25%	25%	24%
Stiffness	52%	38%	66%	49%	62%	54%
Balance difficulties	53%	52%	64%	66%	75%	79%
Walking difficulties	43%	47%	61%	64%	67%	75%
Dyskinesias	17%	14%	34%	34%	39%	35%
Dystonia	27%	22%	41%	36%	41%	41%
Cognitive difficulties	26%	34%	44%	44%	40%	36%
Depression	28%	21%	35%	27%	42%	28%
Anxiety	24%	20%	31%	26%	34%	27%
Stress	30%	24%	35%	31%	33%	31%
Apathy	31%	29%	41%	38%	43%	37%

TECHNOLOGY AND EXERCISE (N=1,500):

- 17% of the entire sample reported watching exercise programs on television, DVDs or computers.
- When asked whether or not Tablets (such as an iPad or Android Tablet) or “smart phones” are used in day-to-day activities (i.e., to browse online, read the news or books, view images, use social networks, and/or use apps, etc.), 40% of the participants reported that they do use such technology in day-to-day activities.
- Only 7% of the participants in this survey use technology (ie.g., “tablets” or “smart phones”) to assist with exercise (e.g., tracking or engaging in exercise).
- Approximately 60% of the participants (across age [**Younger PD group** and **Older PD group**] and disease duration groups [**Early PD group**, **Early Advanced PD group**, **Late Advanced PD group**] indicated that they are interested in learning more about how technology can help individuals with exercise.
- When looking at frequency of utilization of technology across age and disease duration:
 - The **Younger and Early Stage PD group** (50-69 years of age and less than 6 years of PD; 55%) reported greater utilization of technology in day-to-day activities when compared to other **Younger PD** patients in the **Early Advanced Stage PD** (6-10 years; 42%) and **Late Advanced Stage PD** (11+ years; 47%) groups.
 - The use of technology for individuals in the **Older PD group** (70 years and older) and across disease duration (**Early Stage PD**, 34%; **Early Advanced Stage PD**, 31%; **Late Advanced Stage PD**, 32%) were comparable.
 - Regardless of disease duration, the **Younger PD group** used technology more than the **Older PD group**.

DBS VERSUS NON-DBS PARTICIPANTS:

- Generally, the **DBS group** did not engage in more exercise than the **Non-DBS group** [after controlling for age and disease duration].

Summary and Discussion

In recent years, there has been a surge of research exploring factors related to exercise and Parkinson's disease (PD). Exercise has been found to decrease disability and improve quality of life in people with PD^{5,6}. High-intensity exercise has been found to result in symptomatic improvement^{2,4}, and some believe that exercise can be disease modifying^{2,3}.

TAKE HOME POINTS FROM THIS SURVEY:

- The vast majority of the participants reported that exercise is “quite a bit” to “extremely” important (87%). There are many reasons to exercise, and the top five “major” reasons to exercise for participants in this report included: improving health, slowing the progress of PD, maintaining independence, increasing fitness level and increasing energy level.
- Although walking and strength training are the most frequently reported exercises in which the participants engage, there are a host of other exercises in which individuals with PD reported participating, including, but not limited to cycling, Yoga/stretching (i.e., traditional and/or chair Yoga), aerobics, water activities, Tai Chi, dancing, and running.
- This study found that the top 5 perceived barriers to exercise participation included fatigue, health problems related to PD, health problems not related to PD, pain when exercising, and fear of falling/getting hurt.
- Engagement in exercise diminishes with age and disease duration.
- 84% of the participants reported that a Parkinson's doctor has recommended that they exercise. 66% of the participants reported that a Parkinson's doctor has recommended Physical Therapy, and 62% of the participants reported that they have participated in Physical Therapy.
- Despite a large volume of participants engaging in exercise activities, 45% to 57% of participants reported being sedentary for more than 5 hours per day.
- Although technology is not commonly used in exercise programs for individuals with PD, 60% of the participants indicated that they are interested in learning more about how technology can help individuals with exercise.
- Although the DBS group did not report greater activity level than the Non-DBS group (e.g., when matched for age and disease duration), this finding should not minimize the benefits of DBS. For example, research has identified that walking mechanics did improve following DBS; significant increases in length and variability of walking bouts emerged, suggesting improvements in diversity and flexibility of walking patterns. Furthermore, subjective reports of quality of life do remain evident for individuals with DBS²⁷.
- Research has indicated that there is a need to develop and implement intervention strategies to promote an active lifestyle for individuals with PD following DBS, even if clinical improvement is evident following surgery²⁶.

GENERAL IMPLICATIONS AND RECOMMENDATIONS:

- Exercise is an important part of the treatment of PD. There are numerous studies demonstrating that people with PD who engage in exercise have less disability and better physical function compared to those with PD who do not exercise⁷.
- Exercise is thought to improve overall brain health through a variety of means including increases in blood flow and strengthening of brain circuitry².

- Exercise studies in people with PD revealed that walking, strength, balance, fitness levels, flexibility, sleep, and cognitive function may improve with engagement in exercise.
- Many different types of exercise have been shown to be beneficial for people with PD including walking, cycling, strengthening exercises, balance exercises, dance and tai chi^{10, 12, 15, 16, 17, 18, 20, 21, 22}. This finding highlights that there are many exercise options from which to choose.
- Interestingly, there are some functions that can be impaired for individuals with PD, while certain forms of exercise are still attainable. For example there is evidence that some individuals can cycle, despite the inability to walk due to gait disturbance³². Thus, although some difficulties experienced by an individual may seem to be a barrier to exercise, with proper training (i.e., with a Physical Therapist), various exercise routines can be explored and an exercise regimen can be achieved.
- More studies are needed to determine the optimal dose of exercise for persons with PD. However, the Physical Activity Guidelines for Americans published by the US Department of Health & Human Services provides guidelines for older adults (www.health.gov/paguidelines). The guidelines suggest the following:
 - Moderate intensity aerobic exercise (e.g., brisk walking, cycling) for at least 150 minutes (2 hours and 30 minutes) a week or 30 minutes on 5 days per week
 - Moderate intensity strengthening exercises (e.g., weight machines, hand-held weights, exercise bands) 1-3 sets of 8-12 repetitions at least 2 days per week
 - Moderate intensity balance exercises (e.g., backward and sideways walking, standing on one-leg, dance, tai chi) at least 3 days per week.
- Many people experience pain, fatigue or health related problems related and unrelated to PD that might interfere with participation in exercise. It is important to consult with a doctor and/or physical therapist before engaging in exercise to ensure it is done in a safe and effective manner. Asking the doctor for a referral to a Physical Therapist can help people with PD get started on an effective exercise program. A physical therapist can help design or modify exercises to facilitate successful participation.
 - Physical Therapists can help people optimize movement, improve function and reduce disability. Exercise programs tailored to the needs of each individual is recommended.
 - Physical Therapists can help people with PD at any stage of the disease; however, consulting with a physical therapist earlier in the disease course has its advantages and can help with getting started on a safe exercise program.
- Most people experience barriers that can get in the way of exercising regularly. However, there are many strategies to help overcome these barriers and stay on track:
 - Plan ahead and schedule exercise into daily routines
 - Exercise with a family or friend – social support can help provide motivation and encouragement.
 - **Choose exercises that are enjoyable!** Enjoying the activity in which one is engaging will help with sustaining exercise over time.
 - Be informed and get guidance – consult with a Physical Therapist.
 - Take breaks when you feel tired. There is no rush to finish – take your time.
 - Exercise during a time when you feel good and your medications are working their best. This will help to enhance successful participation at a moderate intensity.
 - Work with a Physical Therapist to assist with fatigue and stamina management.

- Psychological factors, such as fear (i.e., fear of falling) can be a significant barrier. Working with a psychologist to address some of the psychological/emotional barriers to exercise may be helpful.
- Though engaging in a planned exercise program may have significant benefits, it is also important to lead an active lifestyle and avoid too much time sitting at any one time. Sedentary breaks, such as bouts of walking after each hour of sitting, can help improve physical activity levels and reduce health risks associated with inactivity³³.
- Many people with PD are interested in learning how to use technology to help with exercise. Since many people engage in walking as a form of exercise and the benefits of walking have been shown in numerous studies, using technology to help with walking is a good way to start.
 - Pedometers measure how many steps are taken each day. Wearing a pedometer can help monitor physical activity levels and provide motivation to walk more. Increasing number of steps taken each day can help avoid a sedentary lifestyle.
 - Metronomes (a device/tool) can help regulate walking tempo to facilitate bigger steps, help with arm swing and a faster walking speed. A metronome application or “app” can be downloaded from a smart phone or tablet. Walking to the beat set on the metronome can help improve quality and efficiency of walking.
- People with Parkinson disease or family members who have questions about exercise can call the toll-free exercise “help-line” (1-888-606-1688 or rehab@bu.edu) at the American Parkinson Disease Association National Rehabilitation Resource Center at Boston University. Callers can speak with a licensed physical therapist who can answer questions about exercise and provide educational materials and resources related to exercise for persons with PD.

Acknowledgements

In this 18th survey, we have reached a new height in the number of participants, and we continue to have an excellent retention rate. 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. 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. Thanks goes to Ann Gottuso, Ph.D., neuropsychology fellow at Cedars-Sinai Medical Center, Los Angeles, CA, for her assistance with the preparation of the data tables. I would like to thank Terry Ellis, PT, Ph.D., NCS, for her assistance with writing the manuscript. Dr. Ellis is an expert in exercise in PD and who is affiliated to the Department of Physical Therapy and Athletic Training, Sargent College of Health and Rehabilitation Sciences, Boston University, and we greatly appreciate her contributions. 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. Additionally, I want to thank Aurore Duboille, Executive Assistant at The Parkinson Alliance and DBS Survey Coordinator, for her assistance with database management, and I want to acknowledge the ongoing dedication of Carol Walton, Chief Executive Officer for The Parkinson Alliance, who assists, at many levels, in making this research possible.

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

References

1. Okun, M. (2013). *Parkinson's Treatment: Ten Secrets to a Happier Life*. Published on Amazon
2. Petzinger GM, Fisher BE, McEwen et al. (2013). Exercise-enhanced neuroplasticity targeting motor and cognitive circuitry in Parkinson's disease. *Lancet Neurology*, 12:716-26
3. Toy, W.A., Petzinger, G.M., Leyshon, B.J., Akopian, G.K., Walsh, J.P., Hoffman, M.V., Vuckovic, M.G., Jakowec, M.W. (2014). Treadmill exercise reverses dendritic spine loss in direct and indirect striatal medium spiny neurons in the 1-methyl-4-phenyl-1,2,3,6-tetrahydropyridine (MPTP) mouse model of Parkinson's disease. *Neurobiol Dis*, 63: 201-9.
4. Fisher, B Intervention that challenges the nervous system confronts the challenge of real-world clinical practice. *Journal of Neurol. Phys. Ther*, 35(3):148-149.
5. Goodwin, VA, Richards, SH, Taylor, RS, et al. (2008). The effectiveness of exercise interventions for people with Parkinson's disease: a systematic review and meta-analysis. *Mov Disord*; 23: 631-640.
6. Keus S.H., Bloem B.R., Hendriks E.J., et al. (2007). Evidence-based analysis of physical therapy in Parkinson's disease with recommendations for practice and research. *Mov Disord*. 2007; 22: 451-460.
7. Tomlinson CL, Patel S, Meek C et al. (2012). Physiotherapy intervention in PD: systematic review and meta-analysis. *BMJ*, 345: e5004
8. Nieuwboer, A., Kwakkel, G., Rochester, L., et al. (2007). Cueing training in the home improves gait-related mobility in Parkinson's disease: the RESCUE trial. *Neurol Neurosurg Psychiatry*; 78: 134-140.
9. Allen, N.E., Sherrington, C., Paul, S.S., Canning, C.G. (2011). Balance and falls in Parkinson's disease: a metaanalysis of the effect of exercise and motor training. *Mov Disord*. 26:l6O5-l6l5.
10. Li F, Harmer P, Fitzgerald K, Eckstrom E, Stock R, et al. (2012) Tai Chi and Postural Stability in Patients with Parkinson's Disease. *N Engl J Med* 366: 511-519.
11. Schenkman, M., Cutson, T.M., KucWbhatla, M., et al. (1998). Exercise to improve spinal flexibility and function for people with Parkinson's disease: a randomized, controlled trial. *J Am GeriatrSoc*; 46: 1207-1216.
12. Uc EY, Doerschug KC et al. (2014). Phase I/II randomized trial of aerobic exercise in Parkinson disease in a community setting. *Neurology*, 83(5):413-25.
13. Schenkman, M., Hall, D.A., Barón, A.E., et al. (2012). Exercise for people in early or mid-stage Parkinson disease: a 16-month randomized controlled trial. *Phys Ther*; 92: 1395- 1410.
14. Corcos DM et al. (2013). A 2-year randomized controlled trial of progressive resistance exercise for Parkinson's disease. *Mov Disord* 28(9):1230-40.
15. Canning CG, Allen NE, Dean CM, Goh L, Fung VS (2012) Home-based treadmill training for individuals with Parkinson's disease: a randomized controlled pilot trial. *Clinl Rehabil* 26: 817-826.
16. Hackney ME & Earhart GM (2009) Effects of dance on movement control in Parkinson's disease: a comparison of Argentine tango and American ballroom. *J Rehabil Med* 41: 475-481.
17. Alberts, J.L., Linder, S.M., et al. (2011). It is not about the bike, it is about the pedaling: forced exercise in Parkinson's disease. *Exerc Sport Sci Rev*, 39(4): 177-86.
18. Uygur, M., Bellumori, M., LeNoir, K., Poole, K., Pretzer-Aboff, I., Knight, C.A. (2015). Immediate effects of high-speed cycling intervals on bradykinesia in Parkinson's disease. *Physiother Theory Pract*. 31(2):77-82

19. Cotman, C.W., Berchtold, N.C., Christie, L.A. (2007). Exercise builds brain health: key roles of growth factor cascades and inflammation. *Trends Neuroscience*, 30(9): 464-72.
20. Hass, C.J. et al. (2012). Progressive resistance training improves gait initiation individuals with Parkinson's disease. *Gait Posture*, 35(4): 669-73.
21. Prodoehl J, Rafferty MR et al. Two-year exercise program improves Physical Function in Parkinson's Disease: The PRET-PD Randomized Clinical Trial. *Neurorehabil Neural Repair* 2015;29(2):112-22.
22. Corcos, D.M., Comella, C.L., and Goetz, C.G. (2012). Tai Chi for patients with Parkinson's disease. *New England Journal of Medicine* 366 (18): 1737-8; author reply 1738.
23. Murray, D.K., Sacheli, M.A., Eng, J.J., and Stoessl, A.J. (2014). The effects of exercise on cognition in Parkinson's disease: a systematic review. *Transl Neurodegener.* 3(1):5
24. Weaver F, Follett K, Hur K, Ippolito D, Stern M. (2005). Deep brain stimulation in Parkinson disease: a metaanalysis of patient outcomes. *J. Neurosurg*; 103(6): 956-67.
25. Weaver FM, Follett KA, Stern M, Luo P, Harris CL, Hur K, Marks WJ Jr, Rothlind J, Sagher O, Moy C, Pahwa R, Burchiel K, Hogarth P, Lai EC, Duda JE, Holloway K, Samii A, Horn S, Bronstein JM, Stoner G, Starr PA, Simpson R, Baltuch G, De Salles A, Huang GD, Reda DJ; CSP 468 Study Group. (2012). Randomized trial of deep brain stimulation for Parkinson disease: thirty-six-month outcomes. *Neurology*. 79(1): 55-65
26. Daneault, J.F., Sadikot, A.F., Barbat-Artigas, S., Aubertin-Leheudre, M., Jodoin, N., Panisset, M., Duval, C. (2014). Physical activity in advanced Parkinson's disease: impact of subthalamic deep brain stimulation. *J Parkinsons Dis.* E-pub ahead of print. <http://www.ncbi.nlm.nih.gov/pubmed/25361545>
27. Rochester, L., Chastin, S.F., Lord, S., Baker, K., Burn, D.J. (2012). Understanding the impact of deep brain stimulation on activity in advanced Parkinson's disease. *J. Neurology*, 259(6):1081-6.
28. Ellis T, Cavanaugh JT, Earhart GM et al. (2011). Factors Associated with Exercise behavior in People with PD. *Phys Ther.* 91(12):1838-48.
29. Ellis, T., Boudreau, J.K., D'Angelis, T.R., Brown, L.E., Cavanaugh, J.T., Earhart, G.M., Ford, M.P., Foreman, K.B., Dibble, L.E. (2013). Barriers to exercise in people with Parkinson Disease. *Phys Ther.* 93(5):628-36.
30. 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.
31. Shrag, A. & Quinn, N. (2000). Dyskinesias and motor fluctuations in Parkinson's disease. A community-based study. *Brain*, 123(11), 2297-305.
32. Snijders, A.H., et al. (2011). Bicycling breaks the ice for freezers of gait. *Movement Disorders*, 26(3): 367-71.
33. Snijders, A.H., Van Kesteren, M., and Bloem, B.R. (2012). Cycling is less affected than walking in freezers of gait. *Journal of Neurol Neurosurg Psychiatry*, 83(5): 575-6.
33. Owen N, Healy GN et al., (2010). Too Much Sitting: The Population-Health Science of Sedentary Behavior. *Exerc Sport Sci Rev.* 38(3):105-113

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