


Unmasking Parkinson's Disease: The Relationship of Grit, Exercise, and Quality of Life

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Abstract

The purpose of this study was to investigate grit, exercise, and quality of life (QOL) among individuals diagnosed with Parkinson's disease (PD). A sample of convenience was used. A survey which included the grit scale, QOL scale, and open-ended questions was distributed to participants ($n = 101$, 51 male and 50 female) who are members of online PD support groups across the United States. Data were analyzed by SPSS 25. Grit values averaged 3.65 ± 0.51 for participants ($n = 101$). When divided into groups, mean grit score for community-based exercisers was 3.78 ± 0.42 and 3.10 ± 0.48 for home-based exercisers. Grit was positively correlated to higher QOL on the Parkinson's disease quality of life (PDQL; $r = +0.293$, $P = .004$). Grit was positively correlated to the emotional component of the PDQL ($r = +0.462$, $P < .001$). Participants with higher grit levels had higher emotional coping responses after being diagnosed with PD, exercised more, and were more willing to self-advocate. With limited rehabilitation visits allowed, physical therapists should be aware of community-based programs to redefine participation roles after diagnosis.

Keywords

Parkinson's disease, grit, exercise, quality of life, physical therapy

Introduction

Parkinson's disease (PD) is a neurodegenerative disorder affecting the basal ganglia of the brain, specifically the substantia nigra (1). For individuals with PD, dopaminergic neuron death occurs within the substantia nigra, leading to decreased control of motor output and decreased control of voluntary movement. Parkinson's disease is the second most common neurological disorder, affecting around 500 000 individuals in the United States (2). Individuals over the age of 60 are most commonly affected by PD. Since there is no known diagnostic test for PD, diagnoses are based on medical history and neurological examination (3).

Since there is no known cause or cure for PD, treatment focuses on the individual and their symptoms. Most individuals diagnosed with PD experience a progression of multidimensional symptoms. Motor-specific symptoms experienced by most with PD include tremor, bradykinesia, postural instability, freezing of gait, difficulty with movement initiation, and rigidity (1–5). Some common non-motor symptoms include anxiety, depression, fatigue, pain, sleep disorders, breathing and respiratory difficulties, and

cognitive changes (1–3). Due to the fact that each individual diagnosed with PD will have a unique progression, treatment for the disease varies immensely. Generally, treatment of PD includes medical and pharmaceutical intervention utilizing dopamine agonists or replacement which needs to be constantly monitored and adjusted. Treatment also focuses on improving the quality of life (QOL) and maintaining independence for as long as possible. Whether the focus for treatment involves medication, rehabilitation, or psychosocial considerations, support will vary depending on the individual (6–15).

Rehabilitation for individuals diagnosed with PD typically strives to regain function, relearn skills, and learn new

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techniques to minimize activity limitations. Some typical rehabilitation techniques may include martial arts (7–14), aquatic therapy (6,15), dance (8,11,12), amplified movement therapies (9,10,13), and endurance and strength training (7). Common motor function outcomes used to evaluate individuals with PD include Berg Balance Scale (16), 6-Minute-Walk-Test (17), Timed Up and Go (18), and forward and backward gait velocity (19). These outcomes are measures of motor skills and are not direct measures of QOL. While the majority of studies evaluate the effect of physical activity on motor outcomes, few address the QOL associated with PD. Common mental/emotional outcome measures used in this area include Frontal Assessment Battery (20), Parkinson's Disease Questionnaire (21), and Parkinson's Disease Quality of Life (PDQL) scale (22). Many different studies found improved efficacy in QOL through the PDQL (6,15).

The International Classification of Functioning, Disability, and Health (ICF) is an international classification system created by the World Health Organization to define, test, and measure functioning and disability (22). With the diagnosis of PD, impairments from neuron death in the substantia nigra and accompanying activity limitations are components of the ICF model which impede participation in life roles. The ICF model provides a framework to evaluate improvements in QOL measures as a result of community participation, support groups, physical therapy interventions, and grit.

The PDQL is an evaluation tool used to determine specific QOL-related outcomes in studies of patients with PD (23). The PDQL is a 37-question self-assessment that participants complete prior to the start of a study, then at the conclusion of a study. It is also commonly used in clinical practice as a measure of function. The PDQL can be divided into 4 subscales: Parkinsonian symptoms, systemic symptoms, social functioning, and emotional functioning. It was developed using preexisting literature in combination with interviews of patients with PD. Frequently recurring elements identified as the most important by patients with PD were included in the construction of the PDQL (22). A higher PDQL score indicates a greater perception of QOL in patients with PD.

Grit is a characteristic commonly found in people with a more positive perception of their situation. Angela Duckworth defines grit as, "Perseverance and passion for long-term goals" (24)^(p1087). Grit includes the desire and effort to accomplish short- and long-term goals regardless of any setbacks or adversity (24,25). Grit is an important characteristic to consider when measuring QOL due to its immense ability to shape a person's perception of life. People who possess high grit levels are much more likely to achieve personal goals than those with low grit levels (24,25). These people tend to have more optimistic views and think of small successes as victories. Grit has been shown to relate more to conscientiousness as opposed to neuroticism, further strengthening the claim that gritty people are more optimistic (24). In terms of reentry into life roles and participation in society, the more grit a person has, the more likely they are to re-enter life roles successfully despite receiving a diagnosis of PD.

A paucity of research exists relating grit and QOL perception in general society. There is even less research comparing grit levels among individuals with any type of serious illness. Specifically, Kwok et al point to a gap in the literature with no research linking psychosocial outcomes and QOL as the primary outcome measure (12). Kwok et al further concluded that the research thus far is inconclusive in terms of creating a cause-effect relationship between exercise and improved psychosocial outcomes and/or QOL. Using the definition of grit by Duckworth et al (24), we hypothesize that higher grit levels will directly correlate with a higher perceived QOL, as well as better reintegration into societal roles in patients with PD. The purpose of our study is to investigate how grit levels and exercise may influence QOL among individuals diagnosed with PD.

Our research questions include:

1. What is the grit level among individuals diagnosed with PD?
2. How does exercise correlate to grit and QOL?
3. How do grit levels correlate to QOL for those diagnosed with PD?

Methods

Survey methods used in this study included a questionnaire exploring the grit scale, exercise, and the PDQL scale. The last portion of the survey asked participants to self-report thoughts on how life was before the diagnosis of PD, what it was like to receive the diagnosis, and how life is now. Participants also had an opportunity to reflect on personal self-advocacy after their diagnosis of PD. Participants were recruited from across the United States through links to online PD support groups from the American Parkinson Disease Association. Participants who accepted the invitation to participate in this study were emailed an online link directing them to the grit and PDQL survey through Survey Monkey™. The survey required 20 minutes to complete. The grit survey allowed researchers to reach a wide population of individuals diagnosed with PD from a variety of settings around the United States. Researchers were blinded to the participants. This strategy highlighted challenges faced by these individuals with PD when working toward participation goals. These writing prompts allowed the researchers to gain a deep, rich description of the experience of grit after receiving a diagnosis of PD.

See Figure 1 for a diagram describing the research methods used in this study. The institutional review board (IRB) at Xxxxxxx approved this study (approval #0011-2018 from Briar Cliff University).

Participants

Inclusion criteria for the study were (a) participants must be diagnosed with PD; (b) may be male or female; (c) live at home; (d) participate in an exercise program; and (d) speak English. Informed consent was obtained before beginning

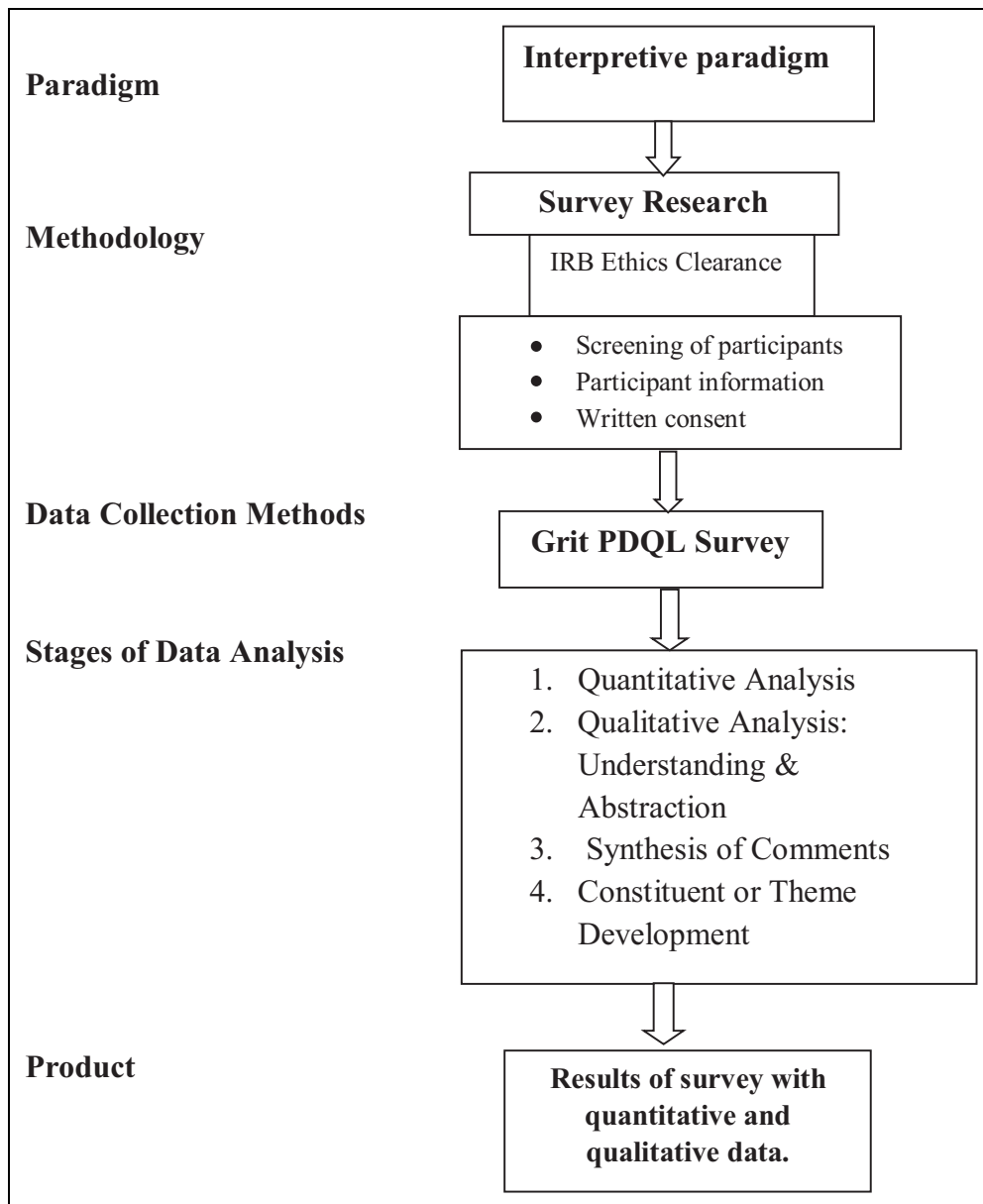


Figure 1. Research methods used, paradigm, methodology, data collection methods, stages of data analysis, and product.

the survey to protect the rights of human subjects who chose to participate.

Instruments/Tools

The grit tool, designed to assess long-term success and perseverance in reaching goals, has been found to have a Cronbach's α value of .80, meaning the tool has good construct validity, meaning it measures what it set out to measure (24–26). It is a 12-item self-report measure of the positive and negative aspects of one's ability to focus on reaching long-term goals. Statements on the grit survey tool are graded on a Likert scale from 1 to 5 and specifically target the ability to set, pursue, and focus on goals. It also assesses one's diligence in working toward goals and dealing with setbacks.

The higher the final grit score, the grittier an individual is considered to be.

The PDQL is a patient-specific measure of QOL that was developed in Holland. It is a valid and reliable self-administered tool exploring QOL for individuals with PD who are community dwellers containing 37 questions (22). The PDQL has 4 subscales that examine Parkinsonian symptoms, systemic symptoms, social function, and emotional function. A higher score indicates a higher QOL (22).

Data Analysis

Quantitative data were analyzed by SPSS 25. Cronbach's α was used to determine the internal consistency of the Grit tool and PDQL tool for this study. Pearson correlation

Table 1. Descriptive Characteristics of Participants, Grit, and QOL Scores.

Phase I: Survey	
Number of participants (total)	101
Persons diagnosed with PD	101
Sex (total):	101
Males (diagnosed with PD)	51
Females (diagnosed with PD)	50
Mean age (years)	
Participants diagnosed with PD	67.7 ± 8.8
Males diagnosed with PD	68.5 ± 8.0
Females diagnosed with PD	66.7 ± 9.8
Mean years with diagnosis of PD	7.9 ± 7.2
Males	8.0 ± 7.7
Females	8.0 ± 6.6
Mean grit scores	
All participants diagnosed with PD	3.65 ± 0.51
Males diagnosed with PD	3.73 ± 0.54
Females diagnosed with PD	3.59 ± 0.46
Mean total PDQL score	120 ± 23
Parkinsonian symptoms mean	3.46 ± 0.68
Systemic symptoms mean	3.23 ± 0.68
Social functioning mean	3.49 ± 0.87
Emotional functioning mean	3.56 ± 0.73

Abbreviations: PD, Parkinson’s disease, QOL, quality of life.

coefficient was used to examine associations between the constructs of grit and QOL.

Interview transcripts were analyzed using the descriptive approach described by Polkinghorne (27), Giorgi (28,29), Thomas and Pollio (30), and Van Manen (31). This process involved a whole-parts-whole type of holistic examination of interview texts to reveal constituents or themes of the experience. This process served as the vertical analysis. A horizontal analysis across all interviews developed the common themes of grit among interviewed participants in this study. To further determine credibility and trustworthiness, a completed summary of themes for the grit experience was shared with individuals diagnosed with PD or caregivers but who were not a part of this study. This process was considered a resonance round for the themes in this study and comments were used to solidify the credibility and trustworthiness of the final themes.

Results

Participants (n = 101) in the study were both male (n = 51) and female (n = 50). Mean age of participants were 67.7 ± 8.8 years. All participants were diagnosed with PD in the last 5 years.

Quantitative Results

Table 1 presents the descriptive characteristics of participants, grit, and QOL scores. Among participants diagnosed with PD (n = 101), grit values averaged 3.65 ± 0.51 on a scale of 1 to 5. Mean grit values for males (n = 51) with PD

(3.73 ± 0.54) were higher than for females (n = 50) with PD (3.59 ± 0.46). Mean value for QOL based on the total PDQL was 120 ± 23. The mean value for each subscale of the PDQL was found. The mean values for Parkinsonian symptoms (3.46 ± 0.68), systemic symptoms (3.23 ± 0.680), social (3.49 ± 0.87), and emotional functioning (3.56 ± 0.73) allowed us to compare scores across PDQL subscales. This was important since our survey platform dropped 1 question of the PDQL (#29) related to transportation. Males scored higher than females on all aspects of the PDQL. Mean number of days per week of exercise was 4.8 ± 3.7 days.

For individuals with PD, overall QOL measured by the PDQL was negatively correlated with years lived with the diagnosis of PD ($r = -0.338, P < .001$), thus the longer one lived with the diagnosis, the lower the QOL. Participants’ grit scores were weakly correlated to QOL as measured by the PDQL ($r = +0.293, P = .004$). The grittier an individual was, the higher the QOL was perceived to be among the participants. Grit was moderately correlated to the emotional construct of the PDQL ($r = +0.462, P < .001$). The grittier an individual with PD was, the better the individual coped emotionally. Grit was also correlated to the subscales of Parkinsonian symptoms ($r = +0.210, P < .05$) and systemic symptoms ($r = +0.250, P < .05$). These correlations were weak but interesting to note. Grit and number of days exercised were also positively correlated ($r = +0.265, P < .007$). Those with higher grit values appeared to exercise more days per week. Table 2 presents the correlation tables. Cronbach’s alpha for the grit scale for individuals with PD was .752 (n = 94).

Qualitative Results

Themes that emerged from the phenomenological interviews included (a) The Reveal: Life Changes; (b) Stay Active: Do Some Thing; and (c) Beyond the Diagnosis: Create a Life-line. One participant wrote about the challenges after the diagnosis is revealed:

I think when you are first diagnosed, everyone goes into that denial. It’s going to find you and get you. There is no hiding. It is just one of those potholes and it is ok to be in the pothole but just don’t get stuck there. Do not get stuck in that pothole!

Once the diagnosis is accepted, participants believed in the importance of moving forward with their new life. One participant stated, “Exercise. Jump right on it. Get on it. If you have a pool get in and swim but don’t do it lazily. Swim like you have a shark behind you.”

Finally, creating a lifeline was a crucial aspect of returning to a full participation in living life albeit different than expected.

I am working on quality of life rather than quantity of life. I have my wife and a good circle of friends and they support me in

Table 2. Correlations.

	Grit Pearson correlation Sig. level (2-tail) N	Grit Pearson correlation Sig. level (2-tail) N	Grit Pearson correlation Sig. level (2-tail) N	Grit Pearson correlation Sig. level (2-tail) N	Grit Pearson correlation Sig. level (2-tail) N
Years lived with DX of PD		-	-	-	-
Pearson correlation	-0.338 ^a				
Sig. level (2-tail)	$P < .001$				
N	86				
QOL on PDQL	-				
Pearson correlation		+0.293 ^a			
Sig. level (2-tail)		$P = .004$			
N		94			
Emotional component on PDQL	-	-			
Pearson correlation			+0.462 ^a		
Sig. level (2-tail)			$P < .001$		
N			94		
Parkinsonian symptoms on PDQL	-	-			
Pearson correlation				+0.210 ^b	
Sig. level (2-tail)				$P < .05$	
N				94	
Systemic symptoms on PDQL	-	-	-	-	
Pearson correlation					+0.250 ^b
Sig. level (2-tail)					$P < .05$
N					94
Days of exercise per week					
Pearson correlation					
Sig. level (2-tail)	+0.265 ^a				
N	$P < .007$				
	101				

Abbreviations: QOL, quality of life; DX, diagnosis.

^aCorrelation is significant at the .01 level (2-tail).

^bCorrelation is significant at the .05 level (2-tailed).

everything that I try to do. They are there for me all the way. People who cut themselves off and who are in denial about things are hurting themselves. You cannot cut yourself off. The social component is extremely important. It's a lifeline.

Discussion

Participants in this study had high levels of grit after being diagnosed with PD. The mean grit score of 3.65 for our participants was higher than Ivy League undergraduates (3.46 ± 0.61), adults aged 25 and older (3.41 ± 0.67), and national spelling bee finalists (3.50 ± 0.67) as determined by Duckworth et al (24). Patients with PD also scored higher on grit than rural and nonrural physicians in Idaho who had an average grit score of 3.30 ± 0.33 per authors Reed et al (32). Von Culin et al reported adults who enjoy questionnaires scored grit values of 3.55 ± 0.78 which was in line with but less than our participants (33). Patients with PD had lower grit scores than physical therapy leaders (3.90 ± 0.47) (34).

Grit and number of years lived with PD were negatively correlated ($r = -0.338$, $P < .001$). Thus, the longer a person

lives with the diagnosis, the greater the potential for lower grit scores. Eskreis-Winkler et al (26) suggest that grit can be learned and even increased according to studies exploring grit over time. Alternatively, perhaps progressive neurological disorders may erode grit.

Grit and QOL as measured by the PDQL were weakly correlated ($r = .293$, $P = .004$), indicating a meaningful relationship between higher grit scores and QOL from the PDQL. A moderate correlation ($r = 0.462$, $P < .001$) found between grit and the emotional subscale of the PDQL suggests that grittier individuals may utilize more positive emotional coping strategies once diagnosed with PD. The PDQL subscales of Parkinsonian symptoms and systemic symptoms revealed a weak positive correlation ($r = 0.250$, $P < .05$) with grit scores. The number of days exercised per week was also weakly correlated with grit ($r = 0.265$, $P < .007$). These correlations were weak but perhaps grit may provide an interesting tool to assess coping strategies of patients with PD.

Individuals diagnosed with PD cope with a life-changing medical diagnosis. It takes grit to pursue life with a positive attitude and not succumb to hopelessness. Many of the

participants confronted their denial and revealed the diagnosis to family, friends, and coworkers. Many more pursued exercise and outreach work with various PD organizations. Not all participants experienced denial upon receiving the diagnosis of PD; however, those who did were able to emerge from denial. Nearly all participants became self-advocates and became educated on PD, taking an active role in the management of the disease. Many led or created support groups. All participants agreed on the importance of movement and exercise in slowing the progression of the disease. The types of exercises included exercise with a personal trainer, rock climbing, swimming, boxing, dancing, LSVT-Big^R, walking, and general exercise. Some participants stayed active by joining PD advocacy communities, starting support groups, and talking to others with PD, connecting them with resources. It appeared from the qualitative data that taking ownership of one's life can positively influence QOL for individuals with PD. Life beyond the diagnosis for many of the participants includes a strong support system of family, friends, and health care providers. With this support, participants were able to overcome the challenges inherent in the diagnosis of PD.

Strengths and Limitations

Strengths of this study included the grit tool itself. It was easy to complete and the Cronbach's α value of .752 suggests adequate construct validity. The initial survey was distributed to 259 individuals and had a good return rate of 39%. The sample size ($n = 101$) for the survey was adequate for a research project incorporating a survey. The writing probes provided a thick, rich description of grit among individuals from around the United States diagnosed with PD which helped inform our quantitative results.

Several limitations exist in this study. The researchers acknowledge that the results of this study do not apply to every person diagnosed with PD. We chose to use the PDQL because it has a high validity and is the most extensive tool for assessing constructs related to QOL among patients with PD (22). While the PDQL has a high Cronbach's α , it was extremely lengthy and challenging for the participants to complete. The large number of 37 questions required by the tool prevented some participants from completing the entire PDQL. Additionally, the survey platform itself was a limitation and dropped one of the PDQL questions leaving us with only 36 questions in the survey despite proofreading and sampling the survey before distribution. The deleted question #29 asked participants to rate difficulties with transport and was a part of the social functioning construct. The Cronbach's α value (.96) for the resulting 36-items tool was nevertheless within an acceptable level of validity and internal consistency. Perhaps using a different survey for QOL and a different survey platform would improve the results.

Future Study Recommendations

Future studies might explore options for how to best measure QOL among individuals with PD using a shorter QOL survey and grit. It would also be interesting to explore grit and QOL among caregivers of people diagnosed with PD. Additionally, specifics of exercise prescription and the link to grit or QOL would also be interesting to explore among caregivers.

Conclusion

Grit is a measure of a person's strategies for meeting challenges and overcoming adversity. Participants with higher grit levels had higher emotional coping responses after being diagnosed with PD, may exercise more than less gritty individuals, and were more willing to self-advocate for themselves and others. With limited rehabilitation visits allowed, physical therapists should have connections to community-based programs to redefine participation after the diagnosis of PD. It may be important for community-based programs to have educational components on grit and QOL to better support individuals diagnosed with PD.

Authors' Note

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Declaration of Conflicting Interests

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Julie A I Thompson, PT, DPT, is a pediatric physical therapist employed by Opening Gaits Pediatric Center in Texas. She has served as a faculty member in several DPT programs across the state of Texas where she has taught in the areas of pediatrics,

geriatrics, wound care, and neurological rehabilitation. She has spent over 32 years as a clinician in both Germany and the United States. She is also a certified NDT practitioner.

Stuart Blatt, PT, PhD, has been in clinical practice for over 30 years. He has been working with people with Parkinson's, Huntington's and Multiple Sclerosis for over 25 years. He is currently a school based physical therapist for the Flint school system. His primary role is to provide physical therapy services to children between the ages 3 to 18 with a variety of orthopedic and neurological disorders. In addition to his clinical duties, he is part of the rehabilitation evaluation team to assess infants and children who were exposed to lead poisoning due to the water crisis and identify any deficits that could affect their ability to maximize their learning potential. Prior to his role in the Flint school system, he served as the interim Chair of the developing DPT program at the Davenport University, Grand Rapids, MI. He also ran his own physical therapy clinic for 7 years that specializes in the care of people with progressive neurological conditions. He served on the membership committee for the MPTA. He currently facilitates 2 weekly exercise groups for people with Parkinson's and Huntington's diseases in South east Michigan. He currently serves on the medical advisory board for the Michigan Parkinson's disease Foundation and presents annually at the state conferences on the effects of exercise on the progression of symptoms associated with Parkinson's and Huntington's disease.