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Abstract

Purpose: Parkinson's disease (PD) is the second most common neurodegenerative disease in the United States. A preponderance of evidence supports exercise and physical activity as an effective intervention to slow the progression of motor symptoms in persons with PD. However, less study has been given to the influence of non-motor symptoms of PD, such as apathy and grit, on adherence to therapeutic exercise programs. The primary aim of this study was to characterize levels of apathy and grit in individuals with PD and explore any relationship to adherence in a community exercise program. Due to the importance of caregiver interaction, this study also examined the non-cognitive traits of caregivers of persons with PD. **Methods:** A descriptive cohort design was used and a convenience sample of individuals with Parkinson's disease and their caregivers attending a Parkinson's support group was collected. **Results:** A total of N=14 participants were included in this study. Levels of grit between persons with PD and caregiver demonstrated a weak positive correlation (r_{pb} = 0.34, p = 0.23). No significant relationships were found between apathy and exercise attendance for PD (r = -0.10, p = 0.83), or among grit and exercise attendance (r = 0.24, p = 0.60). Levels of grit in PD was significantly and negatively related to apathy of caregivers (r = - 0.78, p = 0.04). Grit scores between caregivers and levels of apathy in persons with PD was significantly correlated (r = 0.84, p = 0.02). Findings suggest underlying relationships may exist between levels of grit, apathy, and adherence to exercise programs for persons with PD. **Conclusion:** Further research into the non-motor aspects of PD and their caregivers is warranted. The caregiver relationship plays a critical role in caring for persons with PD and may impact one's adherence to therapeutic exercise.

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ABSTRACT

Purpose: Parkinson's disease (PD) is the second most common neurodegenerative disease in the United States. A preponderance of evidence supports exercise and physical activity as an effective intervention to slow the progression of motor symptoms in persons with PD. However, less study has been given to the influence of non-motor symptoms of PD, such as apathy and grit, on adherence to therapeutic exercise programs. The primary aim of this study was to characterize levels of apathy and grit in individuals with PD and explore any relationship to adherence in a community exercise program. Due to the importance of caregiver interaction, this study also examined the non-cognitive traits of caregivers of persons with PD. **Methods:** A descriptive cohort design was used and a convenience sample of individuals with Parkinson's disease and their caregivers attending a Parkinson's support group was collected. **Results:** A total of N=14 participants were included in this study. Levels of grit between persons with PD and caregiver demonstrated a weak positive correlation (r_{pb} = 0.34, p =0.23). No significant relationships were found between apathy and exercise attendance for PD (r = -0.10, p = 0.83), or among grit and exercise attendance (r = 0.24, p = 0.60). Levels of grit in PD was significantly and negatively related to apathy of caregivers (r = - 0.78, p= 0.04). Grit scores between caregivers and levels of apathy in persons with PD was significantly correlated (r = 0.84, p = 0.02). Findings suggest underlying relationships may exist between levels of grit, apathy, and adherence to exercise programs for persons with PD. **Conclusion:** Further research into the non-motor aspects of PD and their caregivers is warranted. The caregiver relationship plays a critical role in caring for persons with PD and may impact one's adherence to therapeutic exercise.

Keywords: Parkinson's disease, apathy, grit, exercise adherence, caregiver

INTRODUCTION

According to the Global Burden of Disease study, the prevalence of non-communicable diseases, particularly neurological disorders, has been steadily on the rise.[1] Among them is Parkinson's disease (PD), the second most common neurodegenerative disease, which is a significant cause of disability.[1,2] Presently, PD affects 10 million individuals worldwide with roughly 60,000 persons diagnosed in the United States (US) each year.[2] It is estimated there are currently one million individuals in the US living with PD.[2] Additionally, the prevalence of persons newly diagnosed with PD is projected to double by 2040.[2,3] The current costs associated with treatments, social security payments, and loss of income due to PD is estimated at $52 billion per year – making it a formidable public health issue.[3,4] While the influence of motor symptoms such as impaired balance and rigidity on health outcomes is fairly well understood in persons with PD, much less attention has been given to understanding the impact of non-motor symptoms in this population.[5-7] As a result, investigations into the non-motor aspects of PD have become a subject of contemporary interest.

Non-motor symptoms of PD may include cognitive deficits of executive function and memory, impaired emotional processing, and increased levels of depression, apathy, and anxiety.[6,8,9] It is estimated that approximately 50% of persons with PD experience some form of cognitive impairment.[6,8,9] According to the Parkinson's Outcomes Project, a clinical trial with over 12,000 participants, non-motor symptoms had a greater impact on overall health status when compared to motor impairments.[2,3] Persons with PD have demonstrated significant relationships between quality-of-life outcomes and non-motor symptoms of cognitive decline and depression.[9] Emerging evidence suggests there may also be relationships between non-motor symptoms and motor function, quality of life, and caregiver decision-making.[10] For these reasons, there is growing importance to understanding the influence of non-motor symptoms in persons with PD.

Apathy is a common non-motor symptom of PD that affects roughly 30-40% of persons with PD.[6,8,9] Apathy is defined as the lack of interest and indifference to something which would normally excite interest or emotion.[10] It is characterized by diminished motivation, decreased goal-directed behavior, and a flattened affect.[11] The link between cognitive function, depression, and apathy in persons with PD is well established in the literature.[12] Apathy may impact one's ability to adhere to therapeutic exercise programs. Furthermore, the non-cognitive trait of "Grit" has also been identified as a variable which may affect exercise adherence and participation. Grit is a relatively stable intrinsic individual characteristic, unlike apathy which may be a more dynamic "state-like" trait and may change over time.[13] Grit, as defined by Duckworth et al., can be described as perseverance and passion toward long-term goals.[13] Individuals with higher levels of grit can sustain effort and interest toward strenuous challenges despite failure or adversity.[13] There are few investigations on the relationship between levels of grit and health behaviors in persons with PD. However, there is evidence that links levels of grit to health behaviors in non-Parkinson populations. In 2016, Guerrero et al identified grit as a protective factor linked to health behaviors.[14] Similarly, in 2012, Reed et al found important associations between grit and health behaviors related to exercise.[15] Grit may act as a buffer or safeguard against degenerative change and the development of apathy. Therefore, an interaction between grit and apathy may factor into therapeutic interventions for persons with PD. However, it is not yet known how grit and apathy impact adherence to therapeutic exercise programs in persons with PD.

The effects of exercise intervention on apathy in persons with PD have been studied and the benefits of physical activity are generally accepted.[16-21] Prior literature suggests physical activity and exercise intervention in earlier stages of PD, whether completed individually or in a group, may slow disease progression and improve health outcomes.[16-21] Thus, a theoretical foundation exists between exercise or physical activity and non-motor symptoms, such as apathy, in persons with PD. It is important to possess a more complete understanding of the non-motor symptoms of persons with PD in relation to exercise and physical activity. Levels of apathy and grit in persons with PD may play an important role in one's ability to adhere to, and complete, therapeutic exercise interventions. However, there is very little evidence available on the non-motor symptoms apathy and grit in relation to exercise adherence. Studies examining how levels of apathy and grit impact exercise adherence in persons with PD have yet to be explored. Therefore, this study sought to characterize levels of apathy and grit in persons with PD participating in a therapeutic community exercise program. This study also examined whether apathy and grit demonstrate a relationship to adherence to a community exercise program for persons with PD. It was hypothesized that levels of apathy in persons with PD would be negatively related, and levels of grit would be positively related, to overall exercise adherence.

MATERIALS AND METHODS

This study utilized a cross-sectional and observational design. A cohort of persons diagnosed with PD and their caregivers were sampled to study the phenomenon of apathy and grit. A convenience sampling method recruited subjects attending a local PD support group. This included a biweekly, eight-week in duration community therapeutic exercise group specifically designed for persons with PD by a licensed physical therapist. The study was conducted in the Southeastern US during the summer of 2019. All participants with PD had a physician-confirmed diagnosis of idiopathic PD and were classified as Hohen-Yahr (HY) stages I-III. Individuals who were not medically stable or unable to participate in moderate levels of physical activity (classified as HY stages

IV and V) or were unable to follow three-step commands were excluded from this study. Persons with PD having an HY stage greater than III were excluded from participation to avoid confounding results due to the degree of disease severity. Caregivers were self-identified as such and completed an extensive interview with the primary investigator to verify their relationship to the individual with PD as well as their living and social situation. Caregivers were included based on their ability to complete survey data and were excluded if they were unable to participate or complete the required paperwork in any way.

Institutional Review Board (IRB) approval was obtained, and all participants completed and acknowledged consent by signing an informed consent form. The dependent variable of exercise adherence in this study was measured by attendance to a 1 hour, biweekly, 8-week, community exercise program. The exercise program was developed based on prior literature and administered by a licensed physical therapist with extensive experience treating PD in an outpatient clinical setting. The post-intervention assessments were completed one week after the 8-week exercise program concluded.

The independent variables were levels of apathy and grit among individuals with PD and their caregivers and were measured by the 14-item Apathy Scale and the Grit-O scale. The Grit-O and Apathy Scales were administered by the primary investigator prior to the start of the 8-week community exercise program to both the participant and the caregiver. The Apathy Scale has demonstrated suitable psychometric properties in the PD population and is recommended for use by the Movement Disorders Society.[22] The 12-item Grit-O scale has undergone confirmatory factor analysis and demonstrated high internal consistency (Chronbach's alpha = 0.85).[13] Participants also completed the Mini Mental State Examination (MMSE) and the Beck Depression Inventory (BDI), which are considered standard-of-care outcome assessments in persons with PD.[23] The BDI has demonstrated excellent test-retest reliability and is reported to be 0.89 in persons with PD.[24] The MMSE and the BDI were collected to anchor the study outcomes to the prior literature in PD. Data was collected and analyzed using IBM SPSS version 26 (Armonk, NY, 2019).[25] Assumptions tests were performed according to procedures outlined by Cohen, and by Portney and Watkins.[26,27] Non-parametric tests were performed for inferential statistics as the small sample size violated the assumptions of a normal distribution and statistical power. Spearman's Rho test was conducted to test the relationships between independent and dependent variables.

RESULTS

A total of N=14 subjects were enrolled and completed the study procedures (n= 7 patient/caregiver dyads), including n= 7 (PD) and n= 7 (caregivers). A description of the sample and participant demographics can be found in Table 1. Of the seven participants with PD, there were a total of six females and one male. Levels of grit in persons with PD were significantly and negatively correlated with levels of apathy in caregivers (r= -0.78, p= 0.04). Levels of grit between caregivers and levels of apathy in persons with PD were significantly correlated (r= 0.84, p= 0.02). Relationships between apathy, grit, cognition, depression, and attendance in persons with PD (n= 7) are presented in Table 2. Importantly, pre-, and post-exercise levels of apathy and grit were strongly and significantly related to MMSE. Levels of apathy and grit among persons with PD (n = 7) demonstrated a modest but insignificant negative correlation with caregivers (r= -0.50, p= 0.23). Based on the reciprocal nature of the caregiver dyad supported by the Social Network Theory, correlations were analyzed between caregiver apathy and adherence to a community exercise program for persons with PD.[27,28] Levels of grit and exercise attendance of the participants with PD showed a small positive but insignificant correlation (r= 0.24, p = 0.60). Whereas levels of apathy and exercise attendance showed a weak and insignificant negative correlation (r= -0.10, p= 0.83). Levels of grit and attendance were also explored for the caregiver participants. Levels of apathy and exercise program attendance among caregivers revealed a modest negative but insignificant correlation (r= -0.48, p = 0.32). Levels of caregiver grit and exercise attendance revealed a very weak negative and insignificant correlation (r= -0.01, p = 0.85), indicating no practical relationship between the variables. Spearman's rho correlation matrix of measurement variables and lines of best fit are shown in Figure 1. A weak positive correlation was observed between levels of grit and each group, persons with PD and caregivers, and approached significance (r_{pb}= 0.34, n= 14, P= 0.21). A weak and insignificant correlation between levels of apathy and grit among participants with PD (r = 0.09, p= 0.85).

Table 1. Demographic Characteristics and Measurements at Baseline (N=14)

	PD group (n= 7)	Caregiver (n= 7)
Demographics		
Gender (%)		
Female	6 (85.7%)	3 (42.9 %)
Male	1 (14.3%)	4 (57.1%)
Age *Mean*(SD)	77.0 (3.8)	73.5 (12.4)
Race (%)		
Caucasian	100%	100%
Marital Status (%)		
Single	1 (14.3%)	2 (28.6%)

	PD group (n=7)	Caregiver (n=7)
Married	5 (71.4%)	5 (71.4%)
Widowed	1 (14.3%)	0 (0%)
Years with PD *Mean(*SD*)*	8.7 (5.6)	-
Years as Caregiver *Mean(*SD*)*	_	8.3 (7.2)
Relationship to PD partner (%)		
Spouse	_	5 (71.4%)
Friend	_	1 (14.3%)
Child	_	1 (14.3%)
Highest level of Education		
Some college, no degree	2 (28.6%)	3 (42.9%)
College degree or higher	5 (71.4%)	4 (57.1%)
Household Income Level (USD)		
< $60,000	2 (28.6%)	2 (28.6%)
$60,001-80,000	1 (14.3%)	1 (14.3%)
$80,001-100,000	4 (57.1%)	4 (57.1%)
Measurement Variables		
Attendance *Mean(*SD*)*	9.6 (4.1)	_
Becks Depression Inv. *Mean(*SD*)*	9.9 (4.8)	_
MMSE *Mean(*SD*)*	28.9 (1.2)	_
Apathy Scale *Mean(*SD*)*		
Pre-	16.4 (6.7)	9.7 (4.4)
Post-	15.3 (5.9)	11.6 (5.1)
Grit Scale *Mean(*SD*)*		
Pre-	3.7 (0.4)	3.9 (0.4)
Post-	3.4 (0.4)	3.9 (0.5)

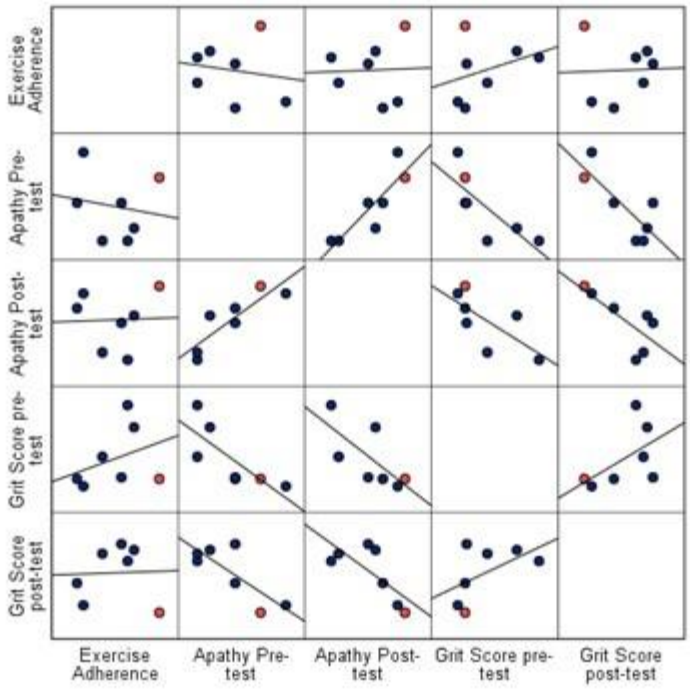
Note. Overall participants average age 75.3 years old (± 9.1). Mini Mental State Exam (MMSE).

Table 2. Spearman's Rho Correlation Matrix for Study Variables

Study Variable	Exercise Adherence	Apathy Scale (pre-exercise)	Apathy Scale (post-exercise)	Grit-O Scale (pre-exercise)	Grit-O Scale (post-exercise)	BDI	MMSE
Exercise Adherence	1.00						
Apathy Scale (pre-exercise)	-0.13	1.00					
Apathy Scale (post-exercise)	0.04	**0.49***	1.00				
Grit-O Scale (pre-exercise)	0.43	1.00	-0.29	1.00			
Grit-O Scale (post-exercise)	0.40	**-0.56***	-0.12	**0.59***	1.00		
BDI	**0.58***	-0.33	-0.16	0.51	.397	1.00	
MMSE	0.01	**-0.82***	**-0.66***	**0.72***	**0.76***	0.58	1.00

*$p < 0.05$; BDI = Beck Depression Inventory; MMSE = Mini Mental State Exam

Figure 1. Correlation Matrix of Measurement Variables.



DISCUSSION

This study examined the relationship between apathy and grit to adherence to a therapeutic exercise program for persons with PD. In large part, the study variable of apathy and grit were unrelated to exercise adherence. Apathy and exercise adherence showed a very weak relationship, and grit had little to no relationship with exercise adherence. Overall, the findings of this sample indicate only a modest level of association exists between levels of apathy between a caregiver and person with PD. That is, as levels of apathy in individuals with PD increased the levels of apathy among caregivers decreased. This supports prior research that has shown a correlation between apathy in persons with PD and caregiver burden.[29] Levels of grit between caregivers and PD showed a modest relationship. Both PD and caregivers had high levels of grit, which supports the hypothesis of a positive correlation between the two groups. The MMSE was strongly and significantly related to levels of apathy and grit in persons with PD. Cognition may be an important moderating factor of these two non-motor symptoms for persons with PD that has yet to be fully uncovered. The remainder of results of this inquiry are mostly incongruent with prior literature.[12,31,32] Despite this fact, this study is an important contribution as it furthers the conversation surrounding the non-motor aspects of disease in an otherwise underrepresented area of inquiry for persons with PD.

Limitations

This study has limitations, and chief among them was a small sample size. The small sample was attributed to unexpected difficulties with a convenience sampling method and an untimely lack of participation in the community exercise program. Based on prior enrollment of the targeted community exercise program it was believed that the sample size would have been at least twice as large than collected in this study. As a result, this sample was underpowered. Furthermore, the participants were generally homogeneous across ethnic, racial, educational, and socioeconomic characteristics. Additionally, the distribution of sexes in this sample is inconsistent with worldwide prevalence of PD.[2,3] Consequently, the authors caution generalizing the results to the broader population of persons with Parkinson's Disease and their caregivers.

CONCLUSION

The caregiver relationship is a critical role that health care providers and public health professionals need to consider when providing treatment intervention, health education, and creating future public health policy. This research study identified a narrow significant relationship between levels of apathy of an individual with PD and their caregiver. In addition, a relationship was identified between levels of grit in persons with PD and levels of grit in caregivers. Although an individual with PD is coping with a neurodegenerative disorder, their potential for improved health outcomes is based on a multitude of individual, community, and societal factors. It is widely known that the health outcomes of an individual with PD may be impacted by the dynamics of the

caregiver. Thus, further research into the social and behavioral interactions between persons with PD and their caregivers is warranted. For example, future research should explore how the role of the caregiver affects the health behaviors of the individual with PD. Additionally, levels of caregiver apathy or grit should be explored as it relates to the levels of behavioral motivation of persons with PD. Lastly, future studies should explore the use of surrogate measures of adherence to therapeutic exercise in relation to the multitude of non-motor symptoms of PD. Perhaps, a grounding factor for future inquiries could rest upon the strength of the connection between the MMSE and other disease factors that is well supported in the literature.[5]

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