



Comparison of self and proxy ratings for motor performance of individuals with Parkinson disease



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ABSTRACT

The impact of Parkinson disease (PD) has been examined in recent years by comparing self-ratings by individuals with PD and proxy ratings by caregivers, communication partners, and/or health care providers. However, the existing evidence is mixed with some researchers suggesting perfect agreement between rater groups while others suggesting differences among rater groups for motor performance of individuals with PD. The current study examined self and proxy perception of performance of individuals with PD for six motor characteristics (gait, rigidity, right and left bradykinesia, rest tremors, and perception of physical effort) based on Unified Parkinson Disease Rating Scale (UPDRS) motor tasks. Participants included 20 individuals with PD, 20 communication partners, and a trained rater. The study compared perceptual ratings and corresponding UPDRS scores as well as rater group differences for perceptual motor ratings. A series of Pearson Product Moment Correlations indicated significant relationship only between self-ratings for gait and rest tremors by individuals with PD and corresponding UPDRS scores ($p < .05$). Further, a multivariate analysis of variance was completed to compare rater group differences. Results indicated significant overestimation of rest tremors by both individuals with PD and communication partners when compared to corresponding ratings by the trained rater. Overall, the study provided evidence for perception deficits among individuals with PD and communication partners regarding motor performance of individuals with PD. Additional studies are needed to further explore the changes in perception abilities of individuals with PD and communication partners with respect to disease duration, disease severity, and other co-morbid factors.

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1. Introduction

Parkinson disease (PD), the second most prevalent geriatric neurodegenerative disorder after Alzheimer's disease, includes combination of different motor, nonmotor, and psychiatric features (Fereshtehnejad & Lökk, 2014). A paradigm shift has been observed in recent years for evaluation of patient outcomes with more studies comparing ratings by different rater groups and clinical variables (Martinez-Martin, Rodriguez-Blazquez, & Frades-Payo, 2012). Among the clinical measures, researchers have used different instruments including Hoehn and Yahr (H & Y) Scale (Hoehn & Yahr, 1967), Schwab and England (S & E) Scale (Schwab & England, 1969), Unified Parkinson Disease Rating Scale (UPDRS; Fahn & Elton, 1987) and PDQ-39 (Peto, Jenkinson, Fitzpatrick, & Greenhall, 1994) to determine the impact of motor symptoms on daily functioning of individuals with PD. Researchers have

compared ratings for awareness of dyskinesias during different medication states (Goetz, Lurgans, Hinson, et al., 2008), freezing of gait, dyskinesias, motor complications (Vitale, Pellecchia, Grossi, et al., 2001), and overall activities of daily living (ADLs; Shulman, Anderson, Gruber-Baldini, et al., 2006). Although the motor performance of individuals with PD has been previously investigated by comparing self-ratings by individuals with PD and proxy ratings by different rater groups (including neurologists, caregivers, and nurses), the evidence has been mixed. While some studies indicate perfect agreement between different rater groups, others indicate differences between self and proxy ratings for motor performance of individuals with PD. The following sections summarize the existing evidence regarding self-perception of motor performance by individuals with PD.

1.1. Perception of gait and ADL tasks by different rater groups

Researchers have examined self-perception of specific gait deficits and ability to perform different ADL tasks by individuals with PD (Amanzio, Monteverdi, Giordano, et al., 2010; Maier,

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Prigatano, Kalbe, et al., 2012; Shulman et al., 2006). Shulman et al. (2006) compared self-ratings by 76 individuals with PD and proxy ratings by a neurologist. Results indicated greatest degree of concordance between self ratings and expert ratings for tasks with greater motor component (i.e., walking) and least concordance for more cognitively dependent tasks (i.e., medication management). In addition, individuals in earlier stages of PD tended to underestimate their disability while those in advanced stages of PD were more likely to overestimate their disability. The authors concluded that self-perception of individuals with PD was more accurate for motoric tasks such as walking and depended on multiple factors including disease severity, setting in which performance is assessed (home versus doctor's office), and nature of task (motor based versus cognitive based).

Self-perception for gait and ADL tasks in individuals with PD has also been studied under different medication states (OFF vs. ON state) by Maier et al. (2012). These authors examined relationship between self-ratings by 28 individuals with PD and corresponding scores on UPDRS tasks during the OFF and ON states. Results indicated more accurate self-perception of motor symptoms only during the OFF state. These authors concluded that dopaminergic overstimulation may be involved with less accurate self-perception of motor symptoms in individuals with PD during the ON state. In contrast, Amanzio et al. (2010) examined self and proxy ratings for ADL performance among individuals with PD during OFF and ON states on the North University Disability Scale. Results indicated similar perceptions between self and proxy ratings and overall less motor impairments in ON versus OFF medication state.

Using a different combination of daily functioning measures (ADL Scale and S & E Scale), Leritz, Loftis, Crucian, et al. (2004) reported patterns of self-underestimation by individuals with PD regarding their motor performance. When cognitive impairments were not taken into consideration, individuals with PD tended to underestimate their deficits on the ADL Scale and overall impairment on S & E Scale. However, once the cognitive status of individuals with PD was included as a covariate, the self and proxy ratings showed similar patterns on the two measures. Similar findings of greater self-awareness deficits in demented individuals with PD compared to the non-demented PD group on UPDRS was reported in another study by Seltzer, Vasterling, Mathias, and Brennan (2001). In conclusion, prior studies have discussed the role of cognitive status on self-perceptions and concluded the need to consider cognitive performance of individuals with PD during comparison of self and proxy perception ratings.

1.2. Perception of dyskinesias

In addition to gait and other motor tasks, prior researchers have investigated self-perception of motor symptoms in individuals with PD. Vitale et al. (2001) examined self-awareness of dyskinesias following specific motor tasks (including standing, gait, finger-tapping, and hand pronation-supination) in 13 individuals with PD. Out of total 13 participants with PD, 38% (i.e., 5/13) participants were completely unaware and 30% (i.e., 4/13) participants were partially aware of their dyskinesias. The authors reported that individuals with advanced PD were more aware of their dyskinesias when compared to individuals with mild PD. Similar changes in self and proxy perception with disease severity were reported by Koerts, van Beilen, Leenders, et al. (2012) for non-motor symptoms in individuals with PD. More agreement was reported between self and proxy ratings for problems in executive functions by individuals with mild PD and their respective caregivers respectively. In contrary, individuals with moderate PD overestimated their deficits compared to their respective caregivers. These authors discussed possible reasons for the mismatch

between self and proxy ratings. It is possible that relatives of individuals with PD possibly recalibrated their impressions regarding functioning of individuals with PD with longer disease duration and thus perceived the motor performance differently than self-ratings by individuals with PD. In addition, presence of depression also demonstrated an influence among individuals with PD as depressed participants self-reported greater deficits than the non-depressed participants with PD (Koerts et al., 2012).

In a different study, Goetz et al. (2008) compared self and proxy ratings for awareness of dyskinesias in individuals with PD. Results indicated deficits among individuals with PD in differentiating their self motor performance for ON and OFF states and ON without dyskinesias from ON with non-troublesome dyskinesias. These authors recommended self-assessment of participants of different levels of fluctuations and dyskinesias in the future to determine the efficacy of self video recordings and home diaries.

1.3. Possible reasons for self-perception deficits in individuals with PD

Vitale et al. (2001) has proposed a psychodynamic hypothesis to explain the self-awareness deficits of dyskinesias. According to this hypothesis, dyskinesias may occur as a result of overtreatment of bradykinesias in individuals with PD. It is possible that the individuals with PD perceive the dyskinesias only when they interfere with a specific motor task rather than presenting by themselves. Another reason for self-awareness deficits in individuals with PD could be possible disruptions in frontal-subcortical connections (Amanzio et al., 2010). The frontoparietal areas have connections with subcortical structures including basal ganglia and other limbic and sensory areas of brain. Individuals with PD may experience self-awareness deficits due to interruptions in these connections and overall basal ganglia dysfunction. In addition, various researchers have attributed reduced self-awareness of dyskinesias to possible influence of dopamine on different cognitive, behavioral, and executive functions (Amanzio et al., 2010; Vitale et al., 2001). Administration of dopamine in depleted circuits typically helps in improving functions within cortical-subcortical loops whereas input of dopamine in non-depleted circuits (i.e., orbitofrontal cortex-ventral striatal areas) leads to dopaminergic overstimulation and subsequent side effects including dyskinesias. Levodopa may thus produce detrimental effects on orbitofrontal and cingulate frontal-subcortical loops which are important for self-awareness functions (Amanzio et al., 2010).

1.4. Aims of the study

Majority of the existing studies have focused either on self-awareness of overall motor performance or on specific symptoms (gait deficits or dyskinesias) in individuals with PD. In addition, prior studies have indicated mixed findings for perception of motor performance by different rater groups. To our knowledge, none of the prior studies have examined self and proxy ratings for multiple motor symptoms within the same set of individuals with PD. It is important to assess how individuals with PD perceive different motor symptoms including gait deficits, rigidity, rest tremors, and bradykinesia while performing different motor tasks. The present study therefore included three rater groups (individuals with PD, communication partners, and a trained rater). The study was completed as part of a larger research project examining self and proxy perception of speech and motor performance by individuals with PD (Parveen & Goberman, 2014). Findings specific to perception of motor performance by different rater groups have been discussed here. Results from the present study can be helpful in determining overall self and proxy perception of different motor variables (including gait, rigidity, bradykinesia, and rest tremors) in individuals with PD. Results from the present study will provide

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