**The Impact of Parkinson's Disease on Social Communication: An Exploratory
Questionnaire Study**

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Abstract

Individuals with Parkinson's Disease (PD) often show breakdown in the interpretation of pragmatic language meaning. However, there is no current standard of care for evaluating social communication dysfunction in PD which affects the persons with PD and their caregivers. Thus, we developed a questionnaire for individuals with PD to evaluate social communication difficulties. *Objective:* The aim of this study was to develop a questionnaire to demonstrate a need for comprehensive management guidelines for individuals with PD regarding social communication skills. This questionnaire will highlight the areas of deficit for the individuals with PD.

Methods: Fifty-one people with self-reported Parkinson's Disease answered 28 survey questions. These questions pertained to emotional expression and perception, social communication, sarcasm/humor and pragmatic skills. Exploratory factor analysis and reliability analysis were performed to identify which items loaded onto the desired factor and to check the internal consistency of the items.

Results: Persons with PD reported changes in emotional expression and perception, social communication, sarcasm and humor, and pragmatic skills domains post PD diagnosis. No correlations were found between age/time since diagnosis and emotional expression, social communication, sarcasm and humor.

Conclusion: The current study provides evidence that persons with PD experience social communication challenges. Therefore, it is crucial to increase awareness of these deficits in PD to recognize the impact of the disease on social communication.

Keywords: Parkinson's Disease, social communication, questionnaire, sarcasm, nonliteral, pragmatics

Introduction

Parkinson's disease (PD) is the second most common neurodegenerative disease, affecting more than 10 million individuals worldwide (Parkinson's Foundation, 2020). It is characterized by progressive motor symptoms including bradykinesia, tremor, and rigidity. Existing treatments for PD often primarily focus on pharmacological and surgical management of these motor symptoms (Kwok, Auyeung, & Chan, 2020). However, people with PD also frequently experience non-motor symptoms, including sleep disorders, neuropsychiatric issues, and cognitive impairments (e.g., Mitkova et al., 2017; Pfeiffer, 2016; Hermanowicz, Jones, & Hause, 2019). While the impact of motor impairments on voice loudness, speech clarity, and reduced facial expressions have been explored extensively (see Sapir et al., 2008 for review), fewer studies have examined non-motor and perceptual aspects of social communication impairments in PD. Previous studies showed that people with PD have difficulty interpreting speaker intentions (e.g., Pell et al., 2014, Monetta et al., 2009), analyzing facial expressions (Alonso-Recio et al., 2020), decoding prosody (Ariatti, Benuzzi, & Nichelli, 2008; Coundouris et al., 2019; Dara, Monetta, & Pell, 2008). Compared to motor outcomes, less attention has been given to the effect of non-motor issues on the psychological needs of persons with PD. Importantly, these impairments, if remained undetected and unaddressed, can significantly affect social communication, and can consequently lead to relationship problems and social isolation (Carcone & Ruocco, 2017). In the current study, we address this gap by exploring the use of a self-report questionnaire on social communication abilities in people with PD.

PD predominantly affects dopamine-producing neurons in the substantia nigra, resulting in motor impairments (e.g., rigidity, tremor, etc.) and non-motor impairments (e.g., sleeping disorders, cognitive decline, neuropsychiatric symptoms, etc.) (Mitkova et al., 2017). It is assumed that the dopaminergic loss in the substantia nigra, and subsequently in the basal ganglia, leads to cortico-striatal-thalamic-cortical circuitries dysfunctions which result in motor

deficits, while social cognition impairments are related to fronto-striatal damage that also occurs in PD (Kennedy & Adolphs, 2012; Xu et al., 2020). Specifically, previous research proposed that dorso-lateral prefrontal areas and nigrostriatal dopaminergic circuits damage results in cognitive decline, such as, inferencing mental states of other people. Likewise, damage to ventromedial, orbitofrontal prefrontal cortex and mesolimbic circuits could result in inability to infer emotional states in others (Alonso-Recio et al., 2020; Bodden, Dodel, & Kalbe, 2010; Koirala et al., 2019; Luo et al., 2014).

Social-pragmatic abilities entail the capability of people to communicate in different contexts, as well as recognize and express communicative intentions (Bara, 2010, Coundouris et al., 2019). That also includes the understanding of the literal and intended meaning especially during the use of metaphors, idioms, sarcasm or proverbs (e.g., Montemurro et al., 2019). Pragmatic abilities rely on higher-order cognitive functions and other paralinguistic abilities such as understanding emotions and identifying facial expressions, all of which can be disrupted in people with PD (Martin & McDonald, 2003; Montemurro et al., 2019). Other deficits can include decision making, understanding humor and creating inferences about abstract concepts which are all integral parts of successful communication (Bodden et al., 2010; Pell et al., 2014). In addition, reduced spontaneous speech production, poor conversational appropriateness, and prosody impairment can also be part of pragmatic profile characteristic of PD (e.g., Montemurro et al., 2019; Roberts & Post, 2018). Recently, the assessment of social communication aspects of people with PD has become a focus of interest, with greater emphasis on components such as social perception and theory of mind (ToM; Martin & McDonald, 2003; Maresca et al., 2020). Several studies have also indicated that ToM is impaired in PD (Bodden et al., 2010; Bora, Walterfang, & Velakoulis, 2015; Yu & Wu, 2013). As discussed above, greater effect of dopamine depletion on the frontal cortex is seen in dorsolateral fronto-striatal circuits, i.e., areas associated with cognitive functions. Thus, it is

reasonable to presume that reductions in cognitive resources results in early social cognition and ToM deficits in PD (Alonso-Recio et al., 2020; Czernecki et al., 2021). Interestingly, Czernecki and colleagues (2021) observe social cognition impairments in about 30% of PD patients, and these impairments can often be found in early stages of the disease. They further suggest that social cognition impairments represent the most common neuropsychological deficit in early-stage PD.

With many individuals worldwide living with PD, researchers and clinicians are assessing PD from both motor and non-motor perspectives. However, successful management of PD is often predominantly focused on controlling motor symptoms, such as drug therapy, speech, and language therapy, etc. As discussed above, we know that individuals with PD can experience major difficulties with social communication including conversation initiation, turn-taking, topic maintenance and appropriately conveying emotion (McNarama & Durso, 2003). Less attention has been given to factors like social cognition and pragmatic skills in PD, and there is limited comprehensive research on the impact of PD on social communication. Most importantly, there is no current standard of care for evaluating social communication dysfunction in people with PD (Hall et al., 2011). Without the appropriate diagnosis of impairment, goals and treatment cannot be established. Therefore, it is essential to identify and establish comprehensive management guidelines for individuals with PD.

Aim of the study

We developed a self-report questionnaire for people with PD that explores their awareness about their social communication skills thereby contributing to the general understanding of the impact of PD on social communication. The goal of our questionnaire is to identify the specific needs of individuals with PD for social communication and accordingly provide data that drives clinical management guidelines. The needs of people with PD could

include self-awareness of deficits, emotional perception, and expression, as well as understanding and using sarcasm, non-literal language, teasing, intonation, and prosody. The questionnaire also includes questions about mood, sense of humor, how PD has impacted their life and elements of social communication including turn-taking, non-verbal cues, facial expressions, and confidence in social settings. Once validated, our hope is that the questionnaire can be used by clinicians to determine the best course of treatment approaches and goals for the individuals with PD. Developing this questionnaire is the first step towards creating a psychometric measurement, using principal component analysis and reliability measures.

Hypotheses

Based on previous literature on social communication in PD (e.g., Bara, 2010, Coundouris et al., 2019), we developed our questionnaire to address several specific hypotheses. We grouped our hypotheses into two main areas: 1) the prevalence of changes in emotional expression, social communication, sarcasm and humor, and pragmatic skills after PD diagnosis; and 2) the relationship between age and emotional expression, social communication, sarcasm and humor, and pragmatic skills.

Hypothesis 1: Changes in emotional expression, social communication, sarcasm and humor, and pragmatic skills are prevalent in people with PD.

For the emotional expression domain, more than half of the participants will ‘agree’ to Q5 (I find it difficult to figure out what people are really thinking), and ‘disagree’ to Q6 (I find it easy to work out peoples’ intentions). For social communication skills, more than half of participants will ‘agree’ to Q8 (I think having Parkinson’s Disease has affected my life), Q11 (I think having Parkinson’s Disease has affected my communication with others), and ‘disagree’ to Q13 (I think having Parkinson’s Disease has not affected my relationships). For sarcasm and humor, more than half of participants will ‘agree’ to Q20 (I think my ability to use

humor has changed since I have been diagnosed). For pragmatic skills, more than half of participants will respond ‘agree’ to Q25 (I have noticed that I use fewer facial expressions since the diagnosis.).

Hypothesis 2: There is a relationship between age/time since diagnosis and emotional expression, social communication, sarcasm and humor

For emotional expression and perception, we hypothesize that the older the participants/longer time since the diagnosis, greater the difficulty to understand others’ intentions (e.g., Q6, I find it easy to work out peoples’ intentions). For social communication skills, we hypothesize that the older the participants/longer time since the diagnosis, more direct they are in communication (e.g., Q10, I find myself being more direct than before my diagnosis). For sarcasm and humor, we hypothesize that the younger the participants are, the more sarcastic they will be (e.g., Q18, I find myself making sarcastic statements during the day).

Methods

Survey construction

A 28-question web-based survey was developed using Qualtrics, an online commercial survey distribution and collection site. Once the participant checked the box indicating having read the consent statement, they were presented with the survey questions concerning different aspects of social communication, such as emotion perception, sarcasm, feelings, emotion production, as well as overall social functioning. Following each question, a 5-point Likert scale (1= Strongly agree, 2= agree, 3=neutral, 4= disagree, 5= strongly disagree) was used to record participants’ responses. The study was approved by the local Institutional Review Board.

Participants

The survey was posted on Qualtrics Panels, an online recruitment service. Only individuals who self-reported to have Parkinson’s Disease participated in the current study.

Inclusion criteria for the participants were: 1) participants diagnosed with PD with no history of dementia and/or stroke, depression; 2) participants aged between 18-99 years; 3) participants had to be fluent in English; and 4) participants responded within a time reasonable for the completion of the survey, determined at around 6 minutes during a soft launch. Originally 65 responses were obtained from the PD participants. Not all responses were accepted for the data analysis. From this cohort, 14 participants were excluded because they did not meet the inclusion criteria. The reasons for exclusion were a) participants gave incomplete or incoherent answers (n=9), and b) participants were diagnosed with dementia (n=2). Participants with a completion time of less than 3 minutes were also excluded from the study to ensure reliability of answers (n=3). With this condition, 51 responses from participants with PD were included for analysis.

Data analysis

We performed principal component analysis (PCA) to examine whether 28 items could be grouped together and load onto any underlying factors together. An exploratory factor analysis of the 28 items social communication questionnaire was performed on the data from 51 participants with PD using SPSS version 27 (IBM SPSS Statistics, 2017; Armonk, NY, USA). Prior to running the analysis, the data were screened by examining descriptive statistics on each item, inter-item correlations, and possible univariate and multivariate assumption violations. The Kaiser-Meyer-Olkin measure of sampling adequacy and Bartlett's test of sphericity were used to determine whether the data were suitable for PCA (Dodge, 2008). A scree plot was used to visually determine the number of factors. We also conducted parallel analysis (PA) and Velicer's Minimum Average Partial (MAP) test (Velicer, 1976) to determine the number of factors to extract from EFA. PA compares the eigen values of a measure against the eigen values from randomly generated data sets. The number of factors to extract corresponds to the number of factors with eigen values greater than the values from randomly

generated data (Hayton et al., 2004). Based on the results from the above-mentioned tests, we performed an EFA with principal component analysis using varimax rotation. To estimate the reliability of the questionnaire, the internal consistency of the items was computed using Cronbach's alpha coefficient.

Results

Descriptive data analysis

A total of 51 participants were included in this survey study, 90.19% were white, 3.92% Black, 1.96% Asian, 1.96% Hispanic and 1.96% other races. The sample's age ranged from 20 to 85 years ($M=61.35$; $SD=16.01$). Mean time since diagnosis was 79.47 months. 80.39% participants reported taking medication for PD whereas, 19.61% did not take any medication for PD. Table 1 summarizes the demographic description for all the participants.

Table 1 here

Exploratory Factor Analysis

The Kaiser-Meyer-Olkin measure of sampling adequacy was .58, indicating that the present data were suitable for principal component analysis. Similarly, Bartlett's test of sphericity was significant ($p < .001$), indicating sufficient correlation between the items to proceed with the analysis. Using PCA, a total of 8 factors were explained by the linear component with eigen values greater than 1.00. The slope of the curve in the scree plot seemed to level out 4 factors. PA analysis predicted that 5 factors should be extracted from the questionnaire. Further, results from original and revised Velicer's MAP test predicted 4 factors respectively.

Based on the results from the above tests, we performed an EFA with PCA using varimax rotation and imposing a four-factor structure. The four factors collectively explained 52.58% of variation in the initial items. Consistent with the best-practices in EFA (Costello & Osborne, 2005), we retained items that loaded highly in their respective factors ($\lambda \leq .50$),

evidenced low cross-loadings ($\lambda \geq .30$), strong communalities ($h^2 \leq .50$), and were not highly redundant with other retained items. From total of 28 initial items, 6 items did not load onto any factor. Table 2 summarizes the rotated loadings for a four factor EFA. Based on the item content, 9 items loaded onto factor 1, 5 items loaded onto factor 2, 4 items loaded onto factor 3, and 5 items loaded onto factor 4.

Table 2 here

Reliability analyses

Internal consistency of the items was computed using Cronbach's alpha coefficient for the 4 factors included in the study. The internal consistency of the 9 items that loaded onto factor 1 was excellent ($\alpha=0.85$; criteria for acceptability=Cronbach's alpha > 0.70); internal consistency for 5 item loadings onto factor 2 ($\alpha=.235$) was poor; internal consistency for 4 item loadings onto factor 3 ($\alpha=.738$) was acceptable; and internal consistency for 5 item loadings into factor 4 ($\alpha=.05$) was poor.

Hypothesis 1: Prevalence of changes in emotional expression, social communication, sarcasm and humor, and pragmatic skills

In the emotional expression domain, the results from the survey showed that 41% of the participants 'agreed' and 8% participants 'strongly agreed' to 'I find it difficult to figure out what people are really thinking'. Twenty two percent of the participants 'disagreed' and 12% 'strongly disagreed' to 'I find it easy to work out peoples' intentions. In the social communication skills, the results showed that 27% 'agreed' and 55% 'strongly agreed' to 'I think having PD has affected my life'. Moreover, 47% of the participants 'agreed' and 22% 'strongly agreed' to 'I think having PD has affected my communication with others'. 18% of the participants 'strongly disagreed' and 27% 'disagreed' to 'I think having PD has not affected my relationships'.

For sarcasm and humor, 47% ‘agreed’ and 10% ‘strongly agreed’ to ‘I think my ability to use humor has changed since I have been diagnosed’. For pragmatic skills, 41% ‘agreed’ and 18% ‘strongly agreed’ to ‘I have noticed that I use fewer facial expressions since the diagnoses.

Hypothesis 2: There is a relationship between age/time since diagnosis and emotional expression, social communication, sarcasm and humor

We performed spearman correlations to study the relationship between age/time since diagnosis and emotional expression, social communication, sarcasm, and humor domains. No significant correlations were seen for the variables of age and emotional expression and perception (e.g., I find it easy to work out peoples’ intentions; $p = .377$); age and social communication (e.g., I find myself being more direct than before my diagnosis; $p = .321$); age and sarcasm/humor (e.g., I find myself making sarcastic comments during the day; $p = .836$).

No significant correlations were seen for the variables of time since diagnosis and emotional expression/perception ($p = .283$); time since diagnosis and social communication ($p = .824$); age since diagnosis and sarcasm/humor ($p = .528$). Figure 1 depicts the participant responses for the self-report questionnaire.

Figure 1 here

Discussion

The current study explored the awareness of social communication skills in people with PD. The self-report questionnaire was developed to understand the impact of the disease on social communication. The goal of our questionnaire was to provide data that demonstrates the need to identify the specific needs of individuals with PD for social communication and to provide management guidelines. Exploratory factor analysis and reliability analysis were

performed to identify which items loaded onto the desired factor and to check the internal consistency of the items. Of the 28 items, 23 items loaded well onto four factors.

Our first hypothesis (Hypothesis 1) predicted changes in emotional expression and perception, social communication, sarcasm and humor, and pragmatic skills domains post PD diagnosis. For the emotional expression domain, we predicted more than half of the participants will indicate that they find it difficult to figure out what people are really thinking. This hypothesis could not be confirmed, as about half of our participants stipulate difficulties with this aspect of social communication. Similarly, over half of the participants reported that they “find it easy to work out peoples’ intentions”, revealing that the incidences of impairments are lower than expected. Since our sample size was limited, future studies with larger samples will need to follow up on these results, including a full battery of neuropsychologic tests for non-demented PD patients (Litvan et al., 2012) as well as social cognition tests.

For social communication skills, we predicted more than half of participants will indicate that PD has affected their life, PD has affected their communication with others, and PD has affected their relationships. About two-third of the participants reported that PD has affected their life, and their communication with others. A little less than half of the participants also reported that PD affected their relationships. These results reveal the devastating effects this disease can have on the psychosocial factors of well-being (Kwok, Auyeung, & Chan, 2020; Schiavolin et al., 2017). Indeed, previous studies have also shown that social cognition impairments in PD can lead to less efficient conversation exchanges with an increased frequency of conversation breakdowns and failed repair sequences (Rinne, 2019), which can further impact the quality of life in people with PD (Miller, 2017). Social communication plays a pivotal role in creating and maintaining relationships and for an overall quality of life. When individuals struggle with social communication, they begin to distance themselves from others and stop participating in preferred activities. This can lead to social isolation and depression

which is common in individuals with PD (Aarsland, 2012). Social communication impairments can also compromise clinical care and increase caregiver burden (Martinez et al., 2018), thereby resulting in reduced communication participation (McAuliffe et al., 2017).

For sarcasm and humor, we predicted that more than half of participants will indicate that their ability to use humor has changed since the diagnosis. This hypothesis was confirmed as more than half of the participants agreed to change in their ability to use humor. For pragmatic skills, we predicted more than half of participants will indicate that they use fewer facial expressions since the diagnosis). More than half of the participants agreed to using fewer facial expressions during conversations. These results are in line with the previous studies. Persons with PD show impaired performance for social-pragmatic skills (Mcnamara & Durso, 2003; Montemurro et al., 2019; Alonso-Recio et al., 2020). These impairments severely affect a person's ability to convey emotions and interest during social conversations. We hypothesize that improving these skills would significantly improve the quality of life for PD. Thus, to develop intervention approaches to improve the quality of life in PD, the first step would be to increase the awareness of social communication deficits in PD using a self-reporting questionnaire.

Our second hypothesis (Hypothesis 2) predicted relationship between age/time since diagnosis and emotional expression, social communication, sarcasm and humor use. This hypothesis was not confirmed as we did not find significant correlations between age/time since diagnosis and any of the three domains. This could be due to the small sample size and thus insufficient statistical power, and future studies need to recruit larger groups of people with PD to test the influence of demographic variables. However, some of the studies in literature have reported effects of age/time since diagnosis and social cognition skills. Processing of emotional prosody (Orbelo et al, 2003; Orbelo et al., 2005) and processing of humor and nonliteral language has been reported to decline in with age (Phillips et al., 2015, Rothermich et al., 2021).

Thus, future studies should test larger groups of participants in order to delineate the influence of disease duration, age, and social communication skills. It will also be crucial to add other measures of communication participation, such as the Communication Participation Item Bank (CPIB; Baylor et al., 2014)

The current study provides evidence that persons with PD self-report social communication deficits. Thus, it is crucial to increase awareness of these deficits in PD to recognize the impact of the disease on social communication. The questionnaire also identifies the specific deficits of individuals with PD in relation to social communication such as self-awareness of deficits, emotional perception and expression, understanding and using sarcasm, non-literal language, and pragmatic skills. However, there are some limitations to the study. One limitation of the present survey study is the small sample size. Large sample size will provide more accurate data which will help in making precise estimations about the questionnaire. Second, five questions (italicized in table 2) showed poor reliability, indicating that they did not precisely measure what they claimed to measure. Future studies will need to adjust the instruments in order to allow reliable self-report measures and replicate the current findings with an adapted questionnaire and a larger sample size. Additionally, objective assessments of social communication/social cognition abilities such as *The Awareness of Social Inference Test* (TASIT; McDonald et al., 2003) need to be compared to the outcomes of the self-report survey.

Conclusion and future directions

While research on social communication in people living with PD is still evolving, our data confirms earlier accounts about the detrimental consequences of less effective communication abilities in people with PD (Miller et al. 2008). These changes can have a devastating effect on quality of life in people with PD and their caregivers, especially concerning communication confidence and autonomy (Johannson et al., 2020; Miller 2017;

Schwartz and Pell 2017; Miller et al. 2008; Prenger et al., 2020). Remarkably, social cognition impairments can be observed in the earliest stages of the disease, prior to the onset of classical motor symptoms (Stanojlovic et al., 2019). Thus, social communication skills should be assessed at an early stage of the disease to quickly identify the deficits and develop effective management strategies. Future research will be essential in comparing this questionnaire to other validated measures of social communication. In addition, performance of persons with PD on this questionnaire should be assessed alongside other assessment tools (for e.g., the Mini-Social Cognition and Emotional Assessment, Mini-SEA; Funkiewiez et al., 2012) to understand how they identify their social communication deficits.

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Table 1. Demographic details of participants

Characteristic	PD (N=51)
Age	61.35 years (16.01)
Gender Identity	Female 45.09% Male 54.90%
Education	Less than high school degree 1.96%, High school graduate 15.68% Some college but no degree 21.56% Associate degree 13.72% Bachelor's degree 25.49% Master's degree 15.68% Doctoral degree 5.88%
Race	Asian 1.96% Black 3.92% White 90.19% Hispanic 1.96% Other 1.96%
Medication Taken for PD	Yes 80.39% No 19.61%
Time since Diagnosis	5.23 years (7.07)

Table 2. Rotated loadings for 4 factor exploratory factor analysis (items in italics did not load onto any factor)

Q.No.	Questionnaire items	Factor 1	Factor 2	Factor 3	Factor 4
Emotional expression and perception					
1.	I am in a happy mood throughout the day.		.841		
2.	I have a positive outlook on life.		.846		
3.	I find it easy to tell if somebody is sad.				.751
4.	I find it hard to tell if somebody is happy.				-.638
5.	I find it difficult to figure out what people are really thinking.				-.522
6.	<i>I find it easy to work out peoples' intentions.</i>				
7.	<i>I find it easy to tell if someone is lying.</i>				
Social communication skills					
8.	I think having Parkinson's Disease has affected my life.			.679	
9.	I am not confident initiating conversations socially.	.529			
10.	I find myself being more direct than before my diagnosis.	.752			
11.	I think having Parkinson's Disease has affected my communication with others.	.565			
12.	I find myself not participating in social activities as much as I used to.			.624	
13.	I think having Parkinson's Disease has not affected my relationships.		.531		
14.	I have noticed changes in the way I communicate since the diagnosis.	.677			
15.	I am sometimes impolite in social situations.	.531			
16.	I feel confident in social situations.		.542		
Sarcasm and humor					
17.	<i>I think I am a sarcastic person.</i>				
18.	I find myself making sarcastic statements during the day.	.718			
19.	I find myself making teasing statements during the day.	.593			
20.	I think my ability to use humor has changed since I have been diagnosed.	.778			
21.	I joke around with my friends.				.646
22.	I think my friends find me funny.				.597
Pragmatic skills					
23.	<i>I do make eye contact during conversations.</i>				
24.	When I speak, I'm sometimes not sure when it's my turn.		-.554		
25.	I have noticed that I use fewer facial expressions since the diagnosis.	.519		.682	
26.	It is easy for me to stay on topic in conversation.				
Speech abilities					
27.	<i>I have monotone voice.</i>				
28.	I often respond in short sentences.			.643	
Cronbach's alpha (α)		.852	.235	.738	.054

Figure 1. Participant responses on the self-report PD questionnaire