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MEASUREMENT OF PATIENT CENTERED OUTCOMES IN PARKINSON'S DISEASE: WHAT DO PATIENTS REALLY WANT FROM THEIR TREATMENT?

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Abstract

Background—Parkinson's disease (PD) impacts several domains of functioning, some of which may be neglected when designing treatment or evaluating outcome using current clinical standards. We therefore argue that taking the patients' perspectives of their condition may allow for a more in-depth assessment of patient goals and subsequent tailoring of care.

Methods—One hundred and forty-eight patients with idiopathic PD completed a modified version of the Patient Centered Outcomes Questionnaire (PCOQ-PD), to evaluate treatment success and expectations from the patient's perspective across 10 motor and non-motor functional domains. We also examined patient subgroups based on importance of improvement in various domains.

Results—Patients' ratings suggested there was substantial variation in functional interference that was generally unrelated to demographic variables. On average, across all domains, patients indicated a 50.32% reduction in symptoms would be successful (range= 40.63% to 58.23%), regardless of treatment experience. Change scores between patients' usual levels of symptom interference and their treatment success levels suggested a greater degree of change was desired in motor versus non-motor domains ($p<.05$). Finally, cluster analyses revealed two patient subgroups based on overall importance of improvement (High vs. Low Importance Endorsement). Notably, the two groups differed in self-reported usual symptom levels despite having similar clinical severity.

Conclusions—We empirically examined treatment success from the PD patient's view as opposed to clinician judgment alone, thereby broadening the set of criteria by which to evaluate outcome. Findings from this exploratory study may guide future treatment emphases and guide patient-provider communication via clarification of patient-defined success.

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Keywords

Parkinson's disease; patient-centered; treatment outcome; success criteria; improvement importance

INTRODUCTION

While motor impairment may be the hallmark of Parkinson's disease, many other behavioral domains are drastically compromised. The 2002 Global Parkinson's Disease Survey revealed that patients' disease severity accounted for only 17.3% of their stated quality of life while psychosocial factors accounted for approximately 60% [1]. Research examining non-motor aspects of PD is comparatively limited, but has steadily gained greater clinical attention [2,3]. However, treatment success in clinical practice is commonly determined by comparing pre- and post-treatment scores on standardized motor examinations or staging systems. Notably, patients' goals following treatment are often different from their physicians', in both magnitude of change and in functional outcome [4–6]. In terms of overall care, Fargel et al. [4] demonstrated that PD patients were significantly less satisfied with their treatment when compared to patients with other chronic illnesses, rating their care on average as 6.6 on a 10-point scale. Furthermore, PD patients are requesting a greater personal role in their care, which has subsequently been associated with increased self-reported patient satisfaction and treatment adherence, even in the absence of apparent changes in motor scores or activities of daily living [7].

In order to convert patients' care perspectives into a focal point of treatment outcome research, certain considerations must be made in statistical methodology. Robinson and colleagues [8,9] have argued that interpreting results of central tendency analyses in clinical studies has various caveats, such as the possibility of significance based on sample size or of the attribution of improvement to a few participants. These investigators have suggested a patient-defined perspective of treatment success rather than relying on metrics established by healthcare providers or third party payers. Additionally, PD patients' expectations for treatment outcome are important to consider when assessing clinical outcome, as studies have suggested that expectations for motor symptom relief mediate placebo and nocebo responses following deep brain stimulation (DBS) manipulations [10,11]. Furthermore, understanding the breadth of behavioral domains impacted by PD may facilitate discussion between patients and their providers in terms of treatment priorities.

The aim of our current study was to implement the Patient-Centered Outcomes Questionnaire (PCOQ-PD), originally developed by Robinson and colleagues [8], and modified for this study to better understand treatment success, expectations, and importance in both motor and non-motor domains from the PD patient's perspective.

PATIENTS AND METHODS

Data were collected from 181 Parkinson's disease patients receiving treatment from the University of Florida Movement Disorders Clinic during their routine care visit. Patients specifically referred to the clinic for DBS candidacy were not included in the study; thus, our sample consisted of a wide range of patients with varying levels of treatment experience. The study protocol was approved by the Institutional Review Board, and each participant provided informed consent. Data were carefully screened to exclude participants with invalid or nonsensical responses or those demonstrating cognitive impairment.

Prior to their clinical visit, patients completed the *Patient Centered Outcomes Questionnaire- Parkinson's disease* (PCOQ-PD), a 40-item questionnaire composed of 4 sections with 10 behavioral or motor domains in each section (pain, fatigue, emotional distress, interference with daily activities, tremor, stiffness in limbs, slowness in movement, walking problems, thinking problems, and sleep problems). The PCOQ, originally devised for assessing multidimensional success criteria in chronic pain, was modified for this study to include behavioral and functional domains affected by PD according to clinical reports. However, the formatting and phrasing of the modified measure was similar to the original PCOQ. There are four sections in the PCOQ-PD, in which patients are asked to rate in each domain: *(1)* their usual levels of self-defined difficulty over the past week, *(2)* their success criteria for treatment outcomes, *(3)* their expectations for their treatment, regardless of their previous treatment experiences, and *(4)* how important it was for them to see improvement (see Appendix 1). Participants used a 101-point numerical rating scale to indicate their rating, anchored by 0 *("None")* to 100 *("Worst Imaginable")* for the first three sections and by 0 *("Not at All Important")* to 100 *("Most Important")* for the fourth section. The original PCOQ has demonstrated adequate reliability (r=0.84 to 0.90), as well as concurrent validity with standardized measures of pain, mood, and disability [9]. Test-retest reliability for the PCOQ-PD has not yet been assessed; however, this measure has shown exceptional concurrent validity with subscales of the Parkinson's Disability Questionnaire (PDQ-39) [12], specifically in the domains of mobility (r=0.54–0.75, p<.001), emotional distress (r=0.71, p<.001), fatigue (r=0.32, p<.001), and ADL (r=0.58, p<.001).

Statistical Methods

Descriptive statistics were generated and normality assumptions were tested for each domain in all four sections of the PCOQ-PD. Pearson's correlations were used to investigate associations between each domain and selected demographic and disease variables. In order to understand the degree of change necessary to be considered a successful treatment outcome, patients' success criteria ratings were subtracted from their usual level ratings to obtain 10 change scores, one for each domain. Repeated measures ANOVAs, corrected for multiple comparisons, were then performed to assess differences in these change scores across domains. Paired-samples t-tests were used to examine the relationship between success criteria and expected outcome for each of the 10 domains. Lastly, a cluster analysis was conducted to derive patient subgroups based upon their ratings of importance of improvement in each domain, thereby identifying patients' treatment priorities. Subsequently, differences in demographic and clinical variables between created clusters were examined.

RESULTS

There were 102 men and 46 women in the final sample, reflecting known sex differences in PD rates. Demographic and disease characteristics are described in Table 1. Data for 19 subjects (10.5%) were unusable due to invalid questionnaire completion, and 14 subjects (7.7%) were excluded due to non-idiopathic PD diagnoses, leaving a total sample of 148 patients. ANOVAs or χ^2 tests comparing the final sample with those who were excluded indicated no significant differences in demographic or disease characteristics (α=.05).

The means, standard deviations, and ranges of scores on the PCOQ-PD are presented in Table 2. In terms of usual symptom reports, patients reported low to moderate levels of usual symptoms in each of the assessed domains, with the lowest level being pain (21.1/100), and the highest level being slowness (42.0/100). Table 3 presents correlations between demographic variables and the PCOQ-PD variables. Generally, age and disease duration were not significantly related to the PCOQ-PD usual symptom ratings. Clinical severity, as measured by the Unified Parkinson's Disease Rating Scale (UPDRS) ON motor

score, was positively associated with all assessed usual ratings ($p<.01$), with the exceptions of fatigue, emotional distress, and sleep. In examining treatment expectations and success criteria, education was negatively correlated with several domains, suggesting that patients with more formal education had greater expectations for treatment outcome and more stringent success criteria. Treatment expectations and success criteria were mostly positively associated with UPDRS scores ($\alpha=.05$). Thus, the severity of patients' motor symptoms was significantly related to lowered expectations for success and less stringent success criteria, although these correlations were notably modest ($r= 0.18$ to 0.34). Other demographic variables (e.g., gender) and clinical variables, such as symptom duration, levodopa dosage, and DBS history, were not significantly related to patients' treatment expectations or to their success criteria.

Mean change scores and standard deviations between patients' usual symptom levels and their success criteria are presented in Table 4. A repeated measures ANOVA with multiple comparisons determining whether change scores differed between functional domains yielded a significant omnibus result [$F(9,1260)= 11.86$, $p<.001$]. Sidak-adjusted individual comparisons indicated that patients viewed greater reductions in slowness, walking difficulties, and fatigue as more necessary for successful treatment outcome than reductions in pain, emotional distress, tremor, stiffness, or thinking difficulties ($p<.05$).

To examine whether patients expected to meet their individually-defined success criteria, a series of paired-samples t-tests were conducted between their expectation rating and their success ratings in each domain. Results revealed a significant relationship only for walking difficulties [$t(135)= 2.14$, $p<.05$], such that their expectations for continued walking problems following treatment ($M= 19.06$, $SD= 22.93$) were greater than their success criterion ($M=15.54$, $SD= 19.39$). This finding suggests that patients expected that their treatment would not satisfactorily address their gait difficulties.

A hierarchical agglomerative cluster analysis (Ward's method, squared Euclidian distance) was used to examine subgroupings of patients based on their ratings of importance of improvement in each domain. A 2-cluster solution was found, essentially dividing patients into a High-Importance Endorsement (HIE) group (N= 61) and a Low-Importance Endorsement (LIE) group (N= 66). Independent samples t-tests and Pearson's chi-square tests revealed that the two clusters did not differ significantly on demographic or clinical variables, with the exception of education [$t(123)=2.06$, $p<.05$], in which the LIE cluster had more formal education. In terms of patients' ratings of usual symptoms across domains, independent-samples t-tests, shown in Table 5, indicated that the HIE group reported higher usual levels of pain, fatigue, tremor, stiffness, and slowness than the LIE group. Individual t-tests were also performed to compare expectations and success criteria for treatment in the two clusters. Results indicated that patients in the HIE cluster reported lowered expectations from their treatment only in the domain of emotional distress (HIE: $M= 17.82$, $SD= 24.48$; LIE: $M= 10.80$, $SD= 12.72$, $t(125)= -2.05$, $p<.05$) than those in the LIE group. The two clusters did not differ in their treatment success criteria for any of the tested domains ($\alpha = .05$).

DISCUSSION

The present study is a preliminary attempt to describe how PD patients define their treatment expectations and criteria for successful outcomes across several functional domains. Originally conceived for chronic pain patients, the PCOQ was modified to address common concerns for PD patients, including both motor and non-motor symptoms. While these issues are important to patients and their clinicians [4], multiple areas of concern have

been minimally addressed from the patients' perspective. We aim to explore these aspects of the disease in order to guide research and patient care appropriately.

Generally, our sample of PD patients reported low to moderate usual levels of daily difficulties across the various domains. These ratings were reflective of their disability score according to Hoehn and Yahr disease staging levels, corroborating other research showing that patient-based self-assessment is related to clinical measures of disability, and that the patients themselves serve as a valuable source in guiding treatment [2,13].

Our results indicated that patients did not expect a complete recovery of their functioning following treatment, nor did they set their success criteria at unreasonably high targets. However, on average, across all domains tested, patients reported being satisfied with a 50.32% reduction in their symptoms from their current state of disability, ranging from 40.63% (pain) to 58.23% (walking difficulties), values which are well beyond the 20–30% reduction in motor symptoms deemed clinically meaningful and realistic [14]. Also, our sample generally reported low to moderate usual levels of functional disturbance; therefore, there may be an even larger discrepancy in more affected or newly diagnosed individuals. The discrepancy between patient and physician goals for treatment may significantly contribute to continuously rising healthcare costs, as patients often "doctor-shop" to find maximal results. Through greater education on the extent of symptom relief in PD treatment and subsequent reevaluation of treatment outcomes with the patient, these costs may be potentially curbed.

Another interesting and somewhat surprising finding in this study was that disease duration and prior treatment experiences, specifically DBS vs. levodopa therapy, *were not related to treatment expectations*, suggesting expectations are based on a more complex network of decisional factors, such as mood or optimism [1]. It is also notable that patient reports of symptom severity were quite variable across domains. These findings provide support for more individualized treatment plans based on the patients' stated complaints that are monitored and adjusted as needed. As the impact of pain and psychosocial distress on functioning gains greater attention in the PD literature, flexibility in practice to effectively accommodate these concerns are warranted [7,15].

This study provided a closer examination of how patients defined success in their treatment across different domains, and revealed several important findings. Of the 10 areas of functioning, patients expressed requiring greater success in motor domains, many of which were also reported as their most prevalent usual symptoms. While results may certainly be reflective of patients' true treatment priorities, another interpretation is that patient ratings may be skewed by taking a more direct interpretation of the question *"What do you consider a successful treatment outcome ?"*, thereby rating motor symptom relief as the marker for success. As the standard for most PD treatments is not focused on psychosocial consequences of the condition or on pain, patients may not even consider these issues when thinking of a successful treatment. Thus, there may be a need for more exploratory research into patient and healthcare provider awareness of relevant non-motor PD symptoms.

Within the motor domain, gait disturbance seemed to be particularly relevant for patients to achieve treatment success, yet was considered least likely to improve. Previous studies have indicated that walking difficulties are highly related to worsened quality of life and increased distress [16], accounting for nearly 30% of issues identified on the Parkinson's Disease Questionnaire (PDQ-39) quality of life summary index [17]. Furthermore, it has been shown that L-dopa has had inconsistent therapeutic effects on gait problems [18], thereby providing some support for patients' lowered expectations for treatment success. As

greater advances are being made in treatment options for gait disturbances [19], patients' expectations for success may eventually follow suit in this particularly salient motor domain.

Fatigue was a frequently endorsed non-motor symptom that held substantial weight in terms of patient-centered success. Fatigue in movement disorders, particularly in PD, is highly prevalent and is often associated with reported disability, psychosocial distress, and pain [20,21]. Conversely, our study revealed that fatigue was one of the few domains that was *not* significantly related to patients' UPDRS motor scores. Furthermore, it was considered significantly more indicative of treatment success to patients than improvements in emotional distress. These results support research suggesting fatigue in PD is poorly understood, and may have separate neurobiological substrates than emotional and physical symptoms common to this population [21].

The cluster analysis indicated that our sample split based on an overall high or low endorsement of symptoms across all problem areas. Interestingly, the clusters did not differ in terms of clinical severity indicators, such as duration, levodopa dosage, or UDPRS scores, suggesting that patients' perceptions of treatment outcome importance are not necessarily dependent upon these measures. Additionally, the two groups did not diverge in most treatment expectations or success criteria, suggesting present symptomatology was the main contributor in importance ratings. However, the clusters did differ in education levels such that those in the low importance cluster had more formal education. In this case, education may be a proxy for socioeconomic status, which has shown to be negatively correlated with access to care and the emotional impact of disease [22].

There are several notable limitations to our study. As the present study employed a novel method to examine patient-centered outcomes in PD, further studies must be done to validate this measure in this population, particularly among a more diverse racial and ethnic sample. Also, multiple correlations were calculated without statistical correction, thus risking the possibility of relationships by chance. Another possible limitation of the study was the exact type of treatment the patient used as a reference for success criteria ratings was not taken into account. Notably, however, we intended to measure patient-centered outcomes across a broad range of PD patients receiving clinical care; thus, specific treatments were not considered as relevant as patients' outcome goals in this study. Along these lines, correlational analyses revealed past or present treatment type did not alter the results. It may be noted that the PCOQ-PD was administered as a self-report measure. Given the substantial proportion of patients excluded from the study due to invalid responses, the PCOQ-PD may not be suitable for this format; future studies examining the reliability and validity of this measure when administered by a trained clinician are warranted. Finally, future work using longitudinal designs is required to determine differences between traditional outcome criteria using nomothetical statistical analyses versus patients' ratings, and how each pertain to healthcare costs and treatment satisfaction.

CONCLUSIONS

Parkinson's disease patients are a heterogeneous group, particularly when it comes to what they expect and desire in their treatment. Because treating PD is a complicated and ever-changing process, it is important to examine the multiple domains impacted by the disease from the patients' perspective. In highlighting patients' most debilitating symptoms and their expectations for care, we aim to encourage a dialogue between patients and providers, thereby creating an environment of greater understanding and, ultimately, more appropriate patient education and treatment strategies.

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Table 1

Participant Demographics

Demographic	*N*	
Age, in years	148	M=65.2, SD= 9.2
Education, in years	144	M=15.2, SD=3.0
Sex		
Male	102	68.9%
Female	46	31.1%
Handedness		
Right	132	89.2%
Left	13	8.8%
PD Type		
Akinetic-Rigid	27	18.2%
Tremor	119	80.4%
Gait-Postural Instability	2	1.4%
History of DBS (Yes:No)	148	69:79
Levodopa Equivalent Dosage (LED) (in mg.)	126	M=808.3, SD=604.7
Duration of Symptoms (in months)	148	M=127.5, SD=96.3
UPDRS ** **Motor Score ON**	135	M=26.7, SD=10.2
Hoehn & Yahr Level	125	M=2.6, SD=3.2

* DBS surgery: Deep Brain Stimulation surgery

** UPDRS: United Parkinson's Disease Rating Scale (given when patients were on their medications)

Table 2

PCOQ-PD Ratings

Domain	N	Mean	Std. Deviation
Usual			
Pain	148	21.11	27.49
Fatigue	148	39.90	27.04
Emotional Distress	148	23.26	25.42
ADL*	148	37.47	31.79
Tremor	148	25.55	27.19
Stiffness	148	32.48	28.63
Slowness	148	41.99	29.64
Walking	148	40.03	32.52
Thinking	148	24.70	26.53
Sleep	148	31.05	31.32
Expected			
Pain	140	12.69	20.26
Fatigue	140	18.49	18.52
Emotional Distress	138	13.54	19.18
ADL*	137	18.78	22.19
Tremor	137	13.54	19.18
Stiffness	137	15.39	18.96
Slowness	137	19.60	22.55
Walking	137	18.92	22.90
Thinking	137	12.80	19.41
Sleep	137	13.75	19.99
Success			
Pain	146	12.28	20.28
Fatigue	146	19.01	19.46
Emotional Distress	146	14.07	19.82
ADL*	146	17.82	21.36
Tremor	143	13.48	19.87
Stiffness	146	15.35	20.59
Slowness	146	18.54	21.55
Walking	145	16.12	20.30
Thinking	146	13.26	19.71
Sleep	147	13.90	18.62
Importance			
Pain	135	46.44	42.32
Fatigue	135	57.18	36.05
Emotional Distress	135	51.88	39.50
ADL*	134	57.91	37.98
Tremor	133	52.02	40.67

Domain	N	Mean	Std. Deviation
Stiffness	135	57.10	37.81
Slowness	134	60.06	34.60
Walking	135	62.24	37.07
Thinking	133	54.71	41.50
Sleep	134	56.01	40.23

* ADL: Interference with Activities of Daily Living

Table 3

Correlations between PCOQ-PD Ratings and Patient Demographics

	Age	Education	Duration of symptoms	UPDRS Total motor score ON
Usual				
Pain	.05	−.17*	−.07	.18*
Fatigue	−.03	−.08	.07	.07
Emotional Distress	−.01	−.01	.16	.07
ADL	.02	−.13	.20*	.24**
Tremor	.08	−.03	.03	.24**
Stiffness	.01	−.18*	.00	.20*
Slowness	.18*	−.20*	.00	.22*
Walking	.08	−.17*	.09	.22**
Thinking	.03	−.16	.08	.20*
Sleep	−.14	−.05	.03	.02
Expected				
Pain	−.03	−.24**	.06	.27**
Fatigue	−.07	−.08	.09	.27**
Emotional Distress	−.10	−.15	.18*	.29**
ADL	.01	−.15	.09	.33**
Tremor	−.03	−.16	.07	.32**
Stiffness	−.03	−.24**	−.03	.34**
Slowness	.01	−.16	.01	.29**
Walking	−.04	−.11	.12	.30**
Thinking	−.06	−.24**	.07	.29**
Sleep	−.01	−.19*	−.03	.29**
Success				
Pain	−.08	−.26**	.07	.18*
Fatigue	−.14	−.10	−.01	.18*
Emotional Distress	−.13	−.03	.05	.10
ADL	−.13	−.13	.15	.22**
Tremor	−.03	−.10	−.04	.29**
Stiffness	−.11	−.19*	.04	.24**
Slowness	−.01	−.18*	.06	.21*
Walking	−.09	−.16	.14	.29**
Thinking	−.03	−.18*	.05	.21*
Sleep	−.07	−.12	.02	.14

*Correlation is significant at the 0.05 level (2-tailed).

** Correlation is significant at the 0.01 level (2-tailed).

Table 4

PCOQ-PD Change Scores Describing Success Criteria as Compared to Usual Symptom Levels

Domain	Mean Change Score	SD
Pain	8.69	27.54
Fatigue	21.49	28.02
Emotional Distress	9.45	25.15
ADL	19.33	30.63
Tremor	12.61	25.12
Stiffness	16.99	28.30
Slowness	23.70	28.94
Walking	23.31	29.46
Thinking	10.63	23.88
Sleep	17.57	29.15

Table 5

Patient Cluster Solution Describing Importance of Improvement in PCOQ-PD Domains and Differences in Usual Symptom Levels

	High Importance Endorsement HIE (N=61)	Low Importance Endorsement LIE (N=66)		
Domain	**Mean (SD)**	**Mean (SD)**	***t Usual Levels***	***p Usual Levels***
Pain	73.52 (34.16)	21.73 (33.20)	−2.35	.02
Fatigue	82.77 (21.33)	35.00 (31.31)	−2.19	.03
Emotional Distress	80.05 (27.76)	25.55 (30.45)	−1.26	.21
ADL	86.64 (21.25)	33.03 (32.32)	−1.80	.07
Tremor	81.56 (28.11)	24.27 (30.64)	−2.08	.04
Stiffness	86.79 (19.11)	31.29 (31.50)	−2.95	<.01
Slowness	85.92 (18.66)	37.23 (30.34)	−2.66	.01
Walking	90.67 (13.46)	38.67 (34.08)	−1.81	.07
Thinking	88.03 (22.77)	25.56 (30.67)	−1.21	.23
Sleep	84.13 (24.00)	34.29 (36.74)	−1.69	.09