Parkinson's Disease from the Patient Perspective:
PRO-PD web-based rating scale assessment in 1077 patients

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INTRODUCTION

For 200 years, the cardinal symptoms of Parkinson's disease (PD) have historically been described as slowness, rigidity, and tremor. Over the past decade, there has been an increasing appreciation for the non-motor aspects of PD, including pain, hyposmia, and constipation.

Recently, the Patient-Reported Outcomes in PD (PRO-PD) was shown to correlate with years since diagnosis, PDQ-39 (r=0.763), PROMIS Global quality of life (r=-0.7293), Hoehn & Yahr (HY) (r=0.5922), Unified PD Rating Scale (r=0.4724), and the Timed-Up-&-Go (r=0.4709); all correlations were P< 0.000.[1] The PRO-PD is a cumulative score derived from 33 unnumbered Likert scales of common PD symptoms, ranging from 0-3300. With individual bars for each symptom, this design permits stratification by symptom.

The purpose of this study was to describe the constellation of parkinsonian symptoms, as experienced by the patient.

METHODS

Data for this analysis were obtained from an ongoing prospective longitudinal internet-based natural history study of PD progression (www.CAMCarePD.bastyr.edu) using the PRO-PD completed online. For this analysis, only baseline data of individuals with a self-reported diagnosis of idiopathic PD (IPD) were used.
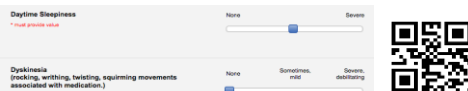
PRO-PD scale can be found at www.PROPD.org.[2]

Individuals were asked to estimate the presence and severity of each symptom, on average, over the prior week. Symptoms were counted as present if they were rated greater than 10/100. Non-motor symptoms included constipation, lack of motivation, depression, socially withdrawn, anxiety, myalgia, fatigue, daytime sleepiness, dizzy on standing, visual impairment, insomnia, REM sleep behavior disorder, drooling, memory impairment, difficulty with comprehension, and hyposmia.

ACKNOWLEDGEMENTS

RESULTS

Cohort Characteristics

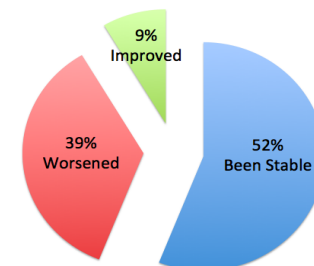|	N=1077 (%)
Age, Years (SD)	63.0 (9.2)
Years Since Diagnosis (SD)	5.2 (5.5)
Gender	
Male	477 (45.7%)
Female	566 (54.3%)
Race/ Ethnicity	
Caucasian	1000 (95.7%)
Black	6 (0.6%)
Hispanic	14 (1.3%)
Native American	3 (0.3%)
Asian/Pacific Islander	9 (0.9%)
Other	13 (1.2%)
Income	
Less than $20,000	54 (5.4%)
Between $20-40,000	143 (14.4%)
Between $40-60,000	146 (14.7%)
Between $60-80,000	153 (15.4%)
Between $80-100,000	132 (13.3%)
Between $100-150,000	197 (19.8%)
More than $150,000	168 (16.9%)
Hoehn & Yahr Stage	
1: 1-sided symptoms, minimal disability	534 (50.8%)
2: Both sides affected, balance is stable	183 (17.4%)
3: Mild to moderate disability, balance affected	290 (27.6%)
4: Severe disability, able to walk and stand without help	33 (3.1%)
5: Confinement to bed or wheelchair unless aided	2 (0.2%)
Don't know	10 (1.0%)

Most Common PD Symptoms

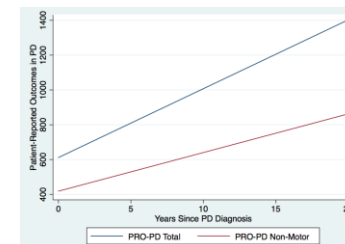| Percent of Patients Reporting Symptom	Symptoms
80-85%	Fatigue, Impaired Handwriting, Hyposmia
70-80%	Memory impairment, Muscle pain, Daytime sleepiness, Slowness, Tremor, Sexual impairment, Balance, Urinary dysfunction, Stooped posture
60-70%	Lack of motivation, Insomnia, Difficulty walking, Anxiety, Difficulty rising, Impaired speech
50-60%	Constipation, Difficulty dressing, Depression, Withdrawn, Acting out dreams, Comprehension, Restless legs, Drooling
40-50%	Dizzy on standing, Visual disturbance, Falls
30-40%	Dyskinesia, Freezing
<30%	Nausea, Hallucinations

Patient Perspective

Symptom Frequency — Idiopathic PD (n=1077), % of participants reporting symptom score >10/100

Symptom Severity — Idiopathic PD (n=1077), 0= asymptomatic/ healthy, 100= severe/ debilitating
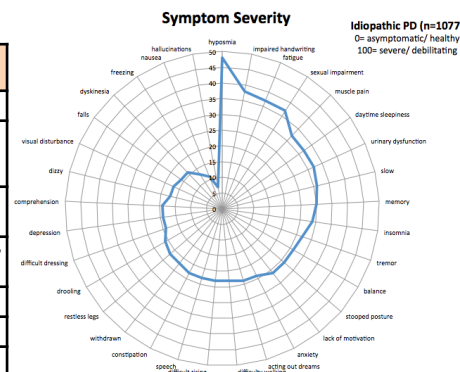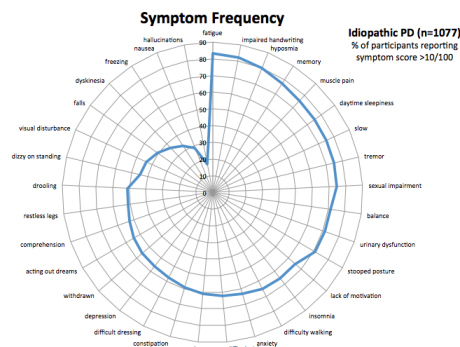
"Over the past 6 months, would you say your disease has: "

- 9% Improved
- 52% Been Stable
- 39% Worsened

Nonmotor Contribution to Disease

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CONCLUSIONS AND FUTURE DIRECTIONS

Using the individual items from the internet-based, patient completed PRO-PD rating scale, nonmotor symptoms are a major contributor to total symptom burden. Many nonmotor symptoms were rated by patients as more severe than their reported motor symptoms. Ongoing studies will evaluate symptoms prior to symptomatic treatment and progression of motor versus nonmotor symptoms over time.

These data draw attention to the unmet needs of patients. While numerous therapies exist to improve motor symptoms, hyposmia, handwriting impairment, fatigue, and sexual dysfunction are being inadequately treated.

Comprehensive care of patients with PD must be patient-centric with shared decision making. Web-based assessment of motor and nonmotor symptoms coupled with emerging remote technology are likely to augment holistic strategies to improve care delivery to patients with PD.

REFERENCES

1. Mischley LK, Lau R, Weiss N. Use of a Self-rating Scale of the Nature and Severity of Symptoms in Parkinson's Disease (PRO-PD): Correlation with Quality of Life and Existing Scales of Disease Severity. npj, accepted 16Apr2017.

2. REDCap: Research Electronic Data Capture direct data entry.