

Title: A Patient-Reported Natural History of Early Parkinson Disease: Cross-sectional Analysis of the MJFF Fox Insight (FI) Platform

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Methodological Question: We explored how to capture and analyze verbatim reports from Parkinson disease (PD) patients, using natural language processing (NLP), in order to provide a cross-sectional profile of the natural history of early PD.

Introduction (Aims):

Our aim was to capture and interpret, using natural language processing (NLP), the verbatim reports of Parkinson disease (PD) patients participating in the Michael J Fox Foundation Fox Insight (FI) research platform (<https://foxinsight.michaeljfox.org>) who completed the PD Patient Reported Outcome of Problems (PD-PROP), in order to build a cross-sectional profile of the problems patients face. The PD-PROP was devised to capture the verbatim accounts of Parkinson disease (PD) patients about their bothersome problems ("What bothers you the most about your PD?"), the functional consequences ("In what way does this problem bother you by affecting your daily functioning?"), and problem severity (0-1-2-3 categorical scale)

Methods:

In the March-November 2017 window, 5703 consenting PD patients completed the FI PD-PROP by computer keyboard entry, including their self-reported date of PD diagnosis. We analyzed the dataset consisting of

4998 PD patients (2648 men, 2350 women) who were within 10 years of PD diagnosis, comparing 0-5 years to 5-10 years durations of illness. Verbatim PD-PROP reports were examined by natural language processing (NLP) and n-gram analyses.

Results:

This cohort, aged 65.0 ± 9.3 years (mean \pm sd) comprised a predominantly well-educated Caucasian population; 3773 patients (2018 men, 1755 women; aged 64.7 ± 9.4 years) were 0-5 years of PD diagnosis (2.2 ± 1.6 years), and 1225 (630 men, 595 women; aged 66.0 ± 8.7 years) were 5-10 years of PD diagnosis (7.7 ± 1.4 years).

Tremor>Hand>Left>Walk>Balance were the most bothersome NLP outcomes reported among the 0-5 year PD duration group compared with Tremor> Walk> Hand >Balance> Leg for the 5-10 year group. After 5 years of PD, Walking, Imbalance and Leg-related problems increased in frequency. Reported problems related to postural instability increased with the age of the patient as well as the duration of PD.

Conclusions:

These analyses provide a preliminary, cross-sectional, patient-reported profile of PD that will be further informed as the PD-PROP cohort grows, longitudinal data accrue, and more granular application of NLP and machine learning techniques are applied.

Disclosures:

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