Refining The Measurement Of Motor And Non-Motor Symptoms in Parkinson’s Disease Patients With Fluctuating Symptoms

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BACKGROUND

- Parkinson’s disease (PD) research and clinical management has traditionally focused on motor symptoms, such as tremors and postural instability, but study findings 1,2,3,4 strongly suggest that non-motor symptoms, such as anxiety and cognitive impairment, are key indicators of patients’ 5 mental health quality of life (QoL).
- Therapy-induced symptom fluctuations (wearing-off and on-off fluctuations) are common after a few years of treatment. Hence, a major aim in the management of PD patients is to reduce the amount of daily symptom fluctuations and the time spent in the off state, i.e., when symptoms are present.
- Measurement of off-time and symptom fluctuations are commonly captured by on/off diaries kept by patients. The Scales for Outcomes in Parkinson’s Disease (SCOPA)-off is an on/off diary designed to measure both the severity and the stability of problems with motor function in PD patients with fluctuating symptoms.
- The SCOPA-off was validated in a sample of PD patients in the Netherlands but has not been validated in a U.S. population. In addition, the SCOPA-DC off does not assess non-motor function.

OBJECTIVES

- Establish the content validity of the SCOPA-DC-off in a U.S. population.
- Determine the feasibility of adding items/domains that measure non-motor function.

METHODS

LITERATURE REVIEW

- Identify the most dominant non-motor symptoms experienced by PD patients with fluctuating symptoms.
- Review the patient-reported outcome (PRO) instruments currently recommended for measurement of non-motor symptoms.
- Search PubMed on Medline for previous research papers using the terms “rating scale”, “nonmotor”, “non-motor”, “daily”, “on-off”, “quality of life”, “SCOPA” in combination with “Parkinson’s”.” or “Parkinson”.

FOCUS GROUPS

- Determine whether the SCOPA-DC-off was well comprehended and relevant in a U.S. population.
- Obtain patient input on the non-motor symptoms that are most relevant to PD patients with fluctuating symptoms.

RESULTS: LITERATURE REVIEW

- Findings from the literature review supported the addition of non-motor symptoms to the SCOPA-DC-off, which was shown to have greater face validity and reliability than the original SCOPA-DC-off, when compared with gold standard measures such as the Unified Parkinson’s Disease Rating Scale (UPDRS) and MDS-UPDRS.
- Although a few PRO-specific instruments 1 were developed with health domains beyond motor function, these instruments were not designed for multiple daily self-reported assessments.

RESULTS: FOCUS GROUPS

- Patient participants were mostly Caucasian (82%), male (67%) and retired (70%). Three quarters experienced at least 2 of the following 3 symptoms: 1) slowed ability to start and continue movements (bradykinesia) and 2) tremors when considering the uncontrollable movements item.
- Patients had difficulty understanding the sleep question in the SCOPA-DC-off and participants struggled to find congruence between the off-time diary and the SCOPA-DC-off.
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CONCLUSION

- Our findings indicated that the inclusion of non-motor symptoms in a PD diary was greatly valued by patients. Meaningful time frames and clarity of response choices were also important factors to patients. A reliable and validated patient-reported diary daily may improve the ability to describe PD progression by accurately measuring both motor and non-motor symptoms. Additional quantitative research is needed to evaluate the psychometric properties of the revised SCOPA-DC-off.