Exploring the Experience of OFF Periods in Parkinson’s Disease

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Background

In Parkinson’s disease (PD), many patients receiving dopaminergic therapy fluctuate between periods in which their symptoms are better controlled, “ON”, and periods during which symptoms return, “OFF”. OFF periods are treatable with various interventions but unfortunately may go undetected in many people with Parkinson’s Disease (PwPD). The study of OFF periods is made challenging by lack of a clear common language around ON and OFF periods between PwPD and their providers as well as significant inter- and intra-individual variability in evolution and manifestations. Better understanding of how PwPD communicate about OFF periods is needed to improve OFF period detection and treatment.

Objectives

To delineate how PwPD communicate about their experience with OFF periods.
To explore what factors, in addition to wearing off of medications, PwPD identify as triggers for OFF periods.

Methods

This was a mixed-methods cross-sectional observational study consisting of 2 phases:

Phase 1: a convenience sample of people with self-reported PD and motor fluctuations were recruited to participate in either:
1. Moderator-facilitated online journaling exercises for 1-2 hours/day for 3 days. A series of questions, interactive graphics, and images were presented to facilitate discussion and elicit detailed descriptions.
2. Semi-structured, moderator-led telephone interviews probing topics including descriptions of OFF, sequence of symptoms, triggers, and communicating these experiences to physicians.

Phase 1 Sample: 11 PwPD participated in the online journaling exercises; 5 female, mean age 57 years (range 45-73), mean age of PD diagnosis 47. 14 PwPD participated in the phone interviews; 8 female, mean age 69.9 years (range 58-84), mean age of PD diagnosis 58.

Phase 2: a survey based on results from Phase 1 was administered to the Fox Insight Study cohort. Fox Insight is an online observational study of PD; 13,359 people with self-reported PD who also reported taking levodopa were invited to complete the survey. The questions deployed and approach to analyses are described in the respective results sections.

Conclusions

We illustrate a broad range of communication strategies that PwPD employ to describe their experience with OFF periods. A majority of PwPD identify triggers for OFF periods distinct from the wearing off of PD medications, especially stress. Our findings delineate the complexity and multidimensionality of OFF periods in PD.

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