

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 Parkinsons 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.

Use of Linguistic Tools Such as Metaphors

Analysis of Phase 1 data revealed that individuals with PD often used metaphors or other forms of figurative language to describe their symptoms.

Weather/Disaster Examples

"Brain fog"
"Like a tsunami"
"Like a dark cloud creeping in and blocking sunshine"

Conflict and Military Examples

"Like a Marching Soldier"
"a Whole-body invasion"
"Like you went through a war"
"I am a warrior"

Use of Both Medical and Lay Terminology to Describe Broad Spectrum of Motor and Non-Motor Symptoms

The following question was deployed Phase 2 on Fox Insight:
"In the space provided below please describe your experience when you are OFF"

Leveraging natural language processing to distill voluminous free-text responses, unsupervised topic models were applied to the first set of responses (n = 1,681). An optimal number of three topics were identified, maximizing cohesiveness and distinctness across potential clusters. The word clouds below showcase each topic output of words and corresponding frequencies from the corpus. Sample quotations from analyzed text also illustrate the spectrum of symptoms and use of lay and medical terminology



"Having this thing decreases manual dexterity"

"I have difficulty walking. I have difficulty coordinating my arms and my legs...I can be bradykinetic"

"I have micrographia, which is one of my Parkinson's symptoms"

"Usually about and hour to thirty minutes before next dose of medicine my hand and fingers start moving and handwriting becomes shakier and smaller"

"With the tremors come a heightened level of anxiety including heart palpitations and some difficulty breathing"

"I feel looosey goosey. My muscles tighten and then release."

Triggers for OFF Symptoms

The survey deployed in Phase 2 on Fox Insight included the following question:

"Are there triggers, such as anxiety or stress, which can bring on an OFF period for you?" and then "What are those triggers?".

Free-text responses were reviewed and categorized.

2,094 respondents completed the survey questions regarding OFF triggers. Mean age 66.5 years (SD 8.5, range 43-84), 1,095 (52.3%) males, mean disease duration 6.14 years (SD 5.09, range 0-22). 1,566 (74.8%) reported triggers that can bring on OFF periods.

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Category	N	Example free-text response
Stress	905	"Any stress is the biggest thing that throws me off"
Anxiety or depression	456	"Anxiety", "When I get worried about things"
Tiredness/fatigue	332	"Too little sleep", "Fatigue is biggest trigger"
Social situations	118	"Having dinner out with friends it seems like I feel the need to take my meds more and sooner", "Crowds", "Unexpected visitors"
Cold or heat exposure	98	"Cold weather"
Family issues	93	"My son", "Having an argument with a loved one", "Mother-in-law", "Family drama"
Anger	64	"Confrontations"
Food intake	49	"Hunger", "Eating meal with protein", "Food delay", "Irregular meals"
Medication-related	31	"Trying to get something done before med time"
Driving	16	"Driving in traffic"
Other, miscellaneous	144	"Loud noises", "too much noise", "airports", "airline travel", "alcohol", "time of day (more off in the evenings)"

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.

These findings are a step toward improving identification of OFF periods in PD.

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