Exploring the Experience of Wearing Off in Parkinson’s Disease: A Qualitative Research Approach
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Objective: To gain insights into how patients with PD communicate about wearing off via an in-depth analysis of patient descriptions of their experiences with this phenomenon.

Background: Wearing off in Parkinson’s Disease (PD) is characterized by the emergence of symptoms prior to scheduled doses of dopaminergic medication, that usually improve after redosing. While treatable, it has a significant negative impact on quality of life. Thus, its diagnosis is essential. Unfortunately, it may go undetected in many patients. Better understanding of how patients with PD communicate about wearing off is needed.

Design/Methods: A convenience sample of PD patients on levodopa therapy reporting wearing off was recruited. Qualitative exploration occurred in 2 phases. Phase 1 included 12 participants and consisted of moderator-facilitated online journaling exercises for 1-2 hours/day for 3 days, while patients were either in the off- or on-medication state. A series of questions, interactive graphics, and images were presented to facilitate discussion and elicit detailed descriptions. Phase 2 involved in-depth semi-structured telephone interviews administered to 14 additional participants.

Results: Four main themes regarding the experience of wearing off in PD emerged (1) During wearing off, patients usually experience multiple motor and non-motor symptoms of varying levels of severity (2) Off symptoms can be triggered as well as mitigated by environmental/situational factors (3) PD patients have a rich language that enables them to understand, contextualize, and communicate about their experience of wearing off, including use of metaphors as well as technical medical terminology (4) The range of linguistic tools employed by patients to describe their wearing off symptoms vary dramatically between and within patients.

Conclusions: Wearing off is a complex, multidimensional phenomenon. Our findings shed light on the means of communication patients with PD employ to describe wearing off. These findings provide a starting point for devising interventions to improve physician-patient communication about wearing off.