

Introduction

While their Parkinson's disease (PD) may appear to be effectively treated, patients do not always inform their physician that symptoms have re-emerged. As a result, the issue may not be addressed during office visits. In support of effective population management of PD, this article provides payers with study insights related to communication gaps in discussions about OFF periods during office visits.

In a linguistic analysis of recorded dialogues between patients with PD and physicians, communication gaps were identified about discussions of OFF symptoms and their management.¹

Another study also focused on communication challenges related to OFF periods in PD. Based on survey results with patients, care partners, and physicians, this study showed how different perceptions

about OFF periods can create challenges in communicating the complexity of OFF periods in office visit dialogues.²

About OFF periods in PD

Patients with PD can fluctuate between ON and OFF periods. During ON periods, PD symptoms are controlled. OFF periods occur when PD symptoms re-emerge, can be unexpected, and occur at any point during the day.^{3,4} OFF periods can even happen when patients are taking their PD therapies as prescribed.³

About 40% of people with PD in the United States experience OFF periods within 4-6 years of therapy.⁵ After 9 or more years of treatment, 70% of patients experience OFF periods.⁵ However, regardless of treatment duration, OFF periods can happen at any point in the disease on any day.⁶

Listening for unheard communication gaps¹

Using actual patient/physician dialogues from a database, a linguistic analysis identified communication gaps related to discussions of OFF period symptoms and their management.

The analysis included 30 recorded conversations between physicians (9 neurologists and 5 movement disorder specialists) and 29 patients with PD; 17 of which also included a caregiver. The dialogues focused on language that represented a spectrum of disease severity with substantial discussion of motor fluctuations, frequency, or management of OFF periods. Follow-up included telephone interviews with a subset of participants who spoke about OFF periods.

Dialogue analysis and telephone interviews revealed 4 areas that contained communication gaps between patients and physicians:

<p>Differences in language</p>	<p>The lack of specific terminology to describe OFF periods was a barrier to effective communication.</p> <ul style="list-style-type: none"> Physicians used a lexicon that focused on the timing and pattern of OFF period symptoms Patients used anecdotal life narratives to describe the unpredictability of OFF period symptoms and the impact of symptoms on their lives
<p>Patient knowledge about OFF periods</p>	<p>Patients had different levels of understanding of disease symptoms and progression.</p> <p>Physicians did not ask questions in a way that connected patients' experiences with OFF periods.</p> <ul style="list-style-type: none"> Only 2 out of 30 dialogues actually included any conversation about why OFF periods occur and how to manage them
<p>Differences in approach to describing OFF periods</p>	<p>Patients reported OFF period symptoms through anecdotal life narratives to describe the impact of symptoms on their lives, without describing specific symptoms.</p> <p>Physicians used terms such as "stiffness," "weakness," "tremor," and "falling," and concentrated only on whether OFF periods occurred, but did not probe regarding the intensity or impact of the OFF periods on their patients' activities.</p>
<p>Attitude toward management of OFF periods</p>	<p>Patients tended to perceive that OFF periods were an inescapable part of disease progression or did not realize the importance of communicating about OFF periods.</p> <p>Many physicians asked patients about both symptoms and dosing times but did not make a conversational connection between the two.</p>

Not surprisingly, the telephone interviews also showed that caregivers played a key role in bridging compromised communication. With widely reported poor patient cognition and impaired speaking ability due to PD, caregivers acted as interpreters during office visits, reporting symptoms that patients may be unable to recognize or report, and reinforcing the legitimacy of patients' concerns.

The authors concluded that physicians, patients, and caregivers were often unaligned in their perceptions of OFF periods. While physicians believed they provided education about OFF periods during office visits, the linguistic analysis showed that information they provided was incomplete, poorly detailed, and often absent.

Communicating about OFF periods of PD in office visits²

OFF periods, where there is a period of re-emergence of symptoms of PD, are associated with poorer health-related outcomes for patients. These episodes include a broad spectrum of motor symptoms, which are unique to each person.

The complexity of OFF periods requires clear communication to understand the patient experience, make treatment decisions, and provide counseling.

In an online survey of people with PD, care partners, and physicians, patients and care partners identified the major barriers to discussing their OFF periods with their doctors. While patients (19%) considered the OFF periods an inevitable part of PD, none of the caregivers agreed.

Major barriers to communicating about OFF periods with physicians

Patients (n=442)

- Simply felt it was part of the disease that could not be improved by their physician
- Variability of symptoms
- Difficulty in describing symptoms

Care partners (n=97)

- Variability of OFF period symptoms
- Patient reluctance to “complain”
- Patient reluctance to admit the impact of the OFF periods on their lives

As for approaches to addressing OFF periods with physicians, the majority of patients and care partners identified a free-flowing dialogue with their physicians and having an agenda as helpful. Almost half of the surveyed patients also looked to online education as a useful source of information about OFF periods. Physicians noted several major barriers to communication about OFF periods during office visits.

Major barriers to communicating about OFF periods with patients

Movement disorder physicians (n=50)

- Patient difficulty in recognizing motor symptoms of OFF periods
- Poor understanding of the relationship between OFF periods and medication timing
- Cognitive impairment in patients

General neurologists (n=50)

- Cognitive impairment in patients
- Patient confusion between dyskinesias and tremor
- Difficulty recognizing motor symptoms of OFF periods

Physicians also rated strategies for facilitating discussions about OFF periods. The most common practices were:

- Including a care partner in the visit
- Fostering a free-flowing dialogue
- Incorporating a teach-back technique

OFF periods of PD involve multiple facets, which often create uncertainty or confusion for patients. This survey revealed several communication barriers among patients, care partners, and physicians, as well as strategies, such as diaries and pre-visit questionnaires, that may help improve clinical interactions and patient understanding of OFF periods.



Key points

Two studies reveal communication gaps in patient/physician discussions of OFF periods in PD

Linguistic analysis identified 4 areas with communication gaps¹: differences in language, patient knowledge about OFF periods, different approaches to describing OFF periods, and attitude toward management of OFF periods

In an online survey, major communication barriers included²:

- Patients felt OFF periods were part of the disease that their physician could not improve, and had difficulty describing the symptoms
- Physicians noted that patients have difficulty recognizing motor symptoms in OFF periods as well as cognitive impairment

References: 1. Levit AV, Zebendon C, Walter L, O'Donnell P, Marras C. *Res Rev Parkinsonism*. 2019;9:3–8. 2. Rastgardani T, Armstrong MJ, Gagliardi AR, et al. *Front Neurol*. 2019;10:892. 3. Olanow CW, Stem MB, Sethi K. *Neurology*. 2009;72(21 suppl 4):S1-S136. 4. Stocchi F. *Expert Opin Pharmacother*. 2006;7(10):1399-1407. 5. Ahlskog JE, Muentner MD. *Mov Disord*. 2001;16(3):448-458. 6. Stocchi F, Antonini A, Barone P, et al. *Parkinsonism Relat Disord*. 2014;20(2):204-211.