

# Use of Figurative Language by People With Parkinson Disease to Describe “Off” Periods

## Clear as Mud

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## Abstract

### Objective

“Off” periods are characterized by the reemergence of motor and nonmotor symptoms in individuals with Parkinson disease (PD) and often negatively affect daily functioning. Individuals’ experiences are diverse and may be difficult to articulate; figurative language is often used by patients to describe such experiences. Our objective was to understand how individuals with PD use figurative language to explain off periods and how experts interpret such expressions.

### Methods

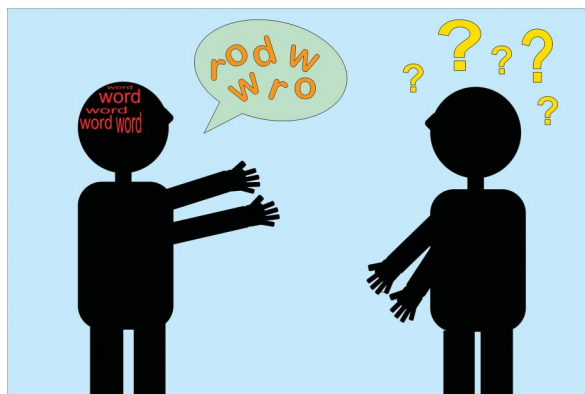
Individuals with self-reported PD participating in the online Fox Insight study were invited to participate in a survey about off periods. Those endorsing off periods were asked to describe their experiences with open-ended free-text responses. Instances where any type of figurative language was used were identified and classified into themes. Three movement disorder neurologists reviewed each phrase and specified what symptoms they felt were likely represented.

### Results

A total of 109 instances of figurative language phrases were identified across descriptions from 86 patients. Allusions to viscous materials (e.g., mud and cement) and effects of chemicals (e.g., drunkenness) were common (18.35% and 17.43% of phrases, respectively). Most phrases were interpreted by the neurologists as representing motor symptoms, but neurologists agreed on what specific symptom was being referred to for only 42 (38.5%) phrases.

### Conclusions

To describe off periods, individuals with PD use various forms of figurative language, but this language is not uniformly interpreted and understood by specialists. Given the subjective interpretation of figurative language, exploring what patients are trying to convey when they use such language is important and could improve patient-physician communication.



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Many individuals with Parkinson disease fluctuate between periods in which their symptoms are better controlled [“on” periods] and periods during which their symptoms return [“off” periods]. Experiences with off periods are diverse and may be difficult to articulate; figurative language may be used by patients to describe such experiences.

Successful exchange of information is a core tenet of patient-physician communication. Figurative language, such as metaphors and similes, involves the use of the nonliteral meaning of a word or phrase to convey information. Figurative language is commonly used in spontaneous speech, where it is often used to describe abstract, complex, or emotionally laden experiences.<sup>1-4</sup> Consistent with the latter, patients with various life-threatening and/or chronic illnesses use figurative language in describing symptoms and experiences.<sup>4,5</sup> For example, patients with cancer often use war or military metaphors. There are few data on the use of figurative language among individuals with neurologic disorders. In 1 study of individuals with motor neuron disease, expressions of entrapment and journeying through landscape were commonly used.<sup>6</sup> Patients with Alzheimer disease and their caregivers liken the disease to a journey with no return.<sup>7</sup> How the use of figurative language by a patient is understood and interpreted by their provider is not known but would be useful to explore toward narrative competency of physicians,<sup>8</sup> and ultimately improving patient-physician communication and patient outcomes.<sup>8,9</sup>

We conducted a study to understand patient experiences with off periods in Parkinson disease (PD).<sup>10</sup> Off periods are characterized by the reemergence of motor and nonmotor symptoms as the effect of dopaminergic therapy wears off. The occurrence of off periods has a significant negative impact on the quality of life (QOL).<sup>11</sup> However, they remain undetected<sup>12</sup> and thus possibly undertreated, perhaps in part because of their substantial heterogeneity, complex manifestations, and interindividual and even intraindividual variability in their expression. To improve understanding of how patients experience off periods and communicate about them, we undertook an in-depth analysis of how patients describe off periods. During this work, we identified several instances in which patients used figurative language. We present those findings

here with 2 main objectives. First, to describe the types of figurative language used and the themes represented in them. Second, to explore how movement disorders experts interpret figurative language used by patients with PD.

## Methods

### Study Design, Sample, and Assessments

This was a cross-sectional survey study. Details of the study design, sample, and assessments have been previously reported.<sup>10</sup> Briefly, a questionnaire was deployed to individuals with self-reported PD participating in the online Fox Insight (FI) study.<sup>13</sup> Inclusion criteria were residence in the United States and taking  $\geq 1$  PD medications. On November 26, 2018, a survey invitation was sent to eligible participants (n = 13,359). Those who clicked on the survey were presented with the following question: “Many individuals with Parkinson disease fluctuate between periods in which their symptoms are better controlled and periods during which symptoms return. We refer to the periods during which symptoms are better controlled as *on*, and periods during which symptoms return as *off*. Based on this definition of *off*, do you experience *off* periods?” Those responding yes progressed to receive the study questionnaire as described.<sup>10</sup>

One of the questions stated: “In the space provided below please describe your experience when you are off.” Open-ended, free-text, character-unlimited responses could be typed in by participants. Responses to this question are the subject of the analysis presented here. Two thousand six hundred eighty-four individuals clicked on the survey link; 49 did not fill out any part of survey, 15 did not endorse diagnosis of PD at their registration visit for FI, 3 had missing age, and 3 had age of PD onset as 0 (considered erroneous entry by the participant). Thus, responses to this question for 2,110 participants were included in this analysis. Each response was reviewed in detail by one of the authors (B.E.). During this review, responses that included any form of figurative language (such as metaphor, simile, or personification) were identified. Responses that included the use of medical terminology were also identified, including verbatim use of the terms bradykinesia, dyskinesia, dystonia, freezing of gait, micrographia, and akathisia, paresthesia(s), and orthostatic hypotension, or misspelled versions of these terms that are clearly identifiable (such as dyskenisia, dyskenisia, and dyskenisia). Responses not using figurative language or medical terminology were considered literal descriptions.

### Qualitative Analysis and Interpretation of Figurative Language

Each use of figurative language was reviewed, and a list of themes or categorizations common to at least 2 of the figurative language phrases was generated (by author B.E.). A neurologist and movement disorders specialist with advanced training in narrative medicine (author S.M.) then reviewed each figurative language phrase and classified it into one or more of the theme

categories listed. The classifications were then reviewed by authors B.E., S.M., and L.M.C., and final categorizations were chosen after discussion. In the process, the original list of themes was refined to consolidate categories.

A goal of this analysis was to determine how a movement disorders specialist who encounters each of the figurative language phrases would interpret them. Specifically, what *symptom or symptoms* the movement disorders specialist believed the patient was referring to with the use of the figurative language.

Three neurologists who are movement disorders specialists (authors L.M.C., S.M., and C.M.) generated a list of common PD symptoms that, based on their expert opinion, could be reported to occur during off periods. Each neurologist then independently reviewed each instance of figurative language. To simulate how a phrase might be encountered in the clinical setting, the neurologist was presented the entire verbatim response as given by the participant, but the part of the response that included figurative language was highlighted. The neurologist classified the figurative language phrase as representing one or more symptoms from the prespecified list. Where necessary, the neurologist could add additional symptoms (not on the list). Finally, the neurologist was required to specify the *one* symptom they thought was most likely to be conveyed by the figurative language phrase. The neurologist had the option to specify “I don’t know” but only as a last resort. The initial list of symptoms and symptoms added subsequent to review is shown in table 1. For analytic purposes, these symptoms were grouped according to general category (motor or nonmotor symptoms that fall under a general category of symptoms based on opinion of the authors).

### Statistical Analysis

Descriptive statistics were used to summarize the study cohort characteristics. Two-sample *t* test and  $\chi^2$  test for homogeneity were used to compare characteristics of those using figurative language vs those who did not. Fleiss kappa was used to compare inter-rater agreement among the 3 neurologists for a given symptom category; inter-rater agreement was considered greater than expected by chance when  $p < 0.05$ . Equality of proportions tests were used to compare, for each pair of symptom categories, the proportion of phrases for which agreement was present among all 3 neurologists on the most likely symptom represented by that phrase; significant difference in proportion was defined when  $p < 0.05$ .

### Standard Protocol Approvals, Registrations, and Patient Consents

This study was performed in accordance with the Declaration of Helsinki. This study and the FI study are approved by the New England Institutional Review Board, and online consent is obtained from each participant at enrollment.

### Data Availability

Data used in the preparation of this article that could be entirely deidentified are available on Fox Den at foxden.michaeljfox.org. Free-text data that could contain identifying information is not available for public sharing to protect participant privacy.

## Results

One hundred nine instances of figurative language were identified in responses across 86 (4.08%) participants. Medical terminology was used to describe experiences during off periods by 168 (8.06%) participants, of whom 4 also used figurative language. The remaining participants used literal language.

Among the 86 participants who used figurative language to describe their experience during off periods, the mean (SD) age was 65.26 (7.81) years and mean disease duration was 7.69 (SD 5.07) years. 98.8% identified as White or Caucasian. Twenty-nine (33.7%) had at least 16 years of education; 25 (29%) had completed a master’s degree. A greater proportion of those using figurative language were women (55 [64.0%] female vs 31 [36.05%] male,  $p = 0.002$ ). In addition, compared with those who used figurative language, those who did not had a shorter disease duration (mean [SD] 6.07 [5.06] years,  $p = 0.004$ ) but were not significantly different in age (mean [SD] 66.62 [8.57] years,  $p = 0.147$ ) or educational attainment (proportion with at least 16 years of education was not significantly higher in those using figurative language vs those who did not;  $p = 0.285$ ).

A variety of figurative devices were used including similes, metaphors, and personification. Themes or categories most commonly represented (table 2) included materials with specific qualities (such as mud or Jell-O) and effects of chemicals (feeling drunk or high). In 14 (12.84%) instances, a specific theme was not represented per se, but the response fell into a category of a group of miscellaneous objects.

### Symptoms Represented by Figurative Language Phrases According to Movement Disorders Neurologists

When the movement disorders neurologists were asked to interpret the figurative language phrases by indicating which symptoms they felt were represented in them, 1 or 2 symptoms were chosen by each neurologist for most phrases. Examples of phrases and the symptoms selected are shown in table 3. For 19 phrases, at least 1 neurologist was not able to pick any symptom (table 4).

As for the symptoms determined by the neurologists to be *most* likely represented by each figurative language phrase (table 4), motor symptoms were most commonly selected: slowness was selected by at least 1 neurologist for 29 (26.6%)

**Table 1** List of Symptoms That the Reviewing Neurologists Used to Specify Which Symptom They Thought Each Figurative Language Phrase Represented

Category	Symptom
<b>Motor-gait/balance/truncal</b>	Imbalance
	Freezing of gait
	<b>Retropulsion</b>
	<b>Shuffling gait or festination</b>
	<b>Flexed/stooped posture</b>
<b>Motor-other</b>	Tremor
	Slowness
	Stiffness
	Dystonia
	Dyskinesia
	Motor weakness
	Motor fluctuation
	<b>Freezing of other body parts</b>
<b>Bulbar/speech</b>	Hypophonia
	<b>Dysarthria</b>
	Trouble swallowing
<b>Sensory</b>	Restlessness/akathisia
	Dysesthesia/paresthesia
<b>Cognitive</b>	Concentration
	Memory difficulty
	Inattentiveness
	<b>Bradyphrenia</b>
	<b>Cognitive impairment</b>
<b>Psychiatric</b>	Depression
	Anxiety/panic
	<b>Dissociation</b>
	Apathy
<b>Fatigue/malaise</b>	Fatigue
	<b>Malaise</b>
<b>Autonomic/gastrointestinal</b>	<b>Dizzy/lightheaded</b>
	<b>Nausea</b>

Symptoms in bold are those added during review.

phrases, stiffness for 29 (26.6%) phrases, and tremor for 15 (13.8%) phrases. Among nonmotor symptoms selected, akathisia/restless (12 [11.0%]) and concentration problems (12 [11.0%]) were most common.

## Agreement Among Movement Disorders Neurologists on the Most Likely Symptom Represented by Figurative Language Phrases

All 3 neurologists chose the same symptom in 42 (38.5%) instances, with stiffness being most commonly agreed on (11 phrases), followed by imbalance (7 phrases) and slowness (6 phrases). Two of 3 neurologists chose the same symptom for 44 (40.4%) phrases. Inter-rater agreement for 2/3 or 3/3 neurologists for a given category was high for all categories except 19 phrases in which at least 1 neurologist felt unable to pick a given symptom (“I really don’t know”; table 4). In 3 instances, all 3 neurologists chose the “I really don’t know” option.

Nonmotor symptoms were selected as most likely represented by a given phrase by all 3 neurologists in 27 cases, whereas a motor symptom was selected in 51 cases (table 4). The proportion of phrases with *complete* agreement between neurologists as to the specific symptom represented was significantly lower in instances where all neurologists selected a nonmotor vs a motor symptom (10 [9.2%] vs 32 [29.4%],  $p = 0.0002$ ). Proportions of phrases selected as representing a given category, and significant differences in these proportions between categories, are shown in table 5.

## Discussion

Off periods, or the reemergence of motor and nonmotor symptoms as the effect of dopaminergic therapy wears off, are common in PD and have a significant negative impact on QOL.<sup>11</sup> They are often treatable with medication adjustments, adjunctive medications, or surgical interventions.<sup>14</sup> Thus, their detection is critical. Indeed, querying patients for medication-related complications is part of the standard of care in PD.<sup>15</sup> Although questionnaires may be useful to screen for off symptoms,<sup>16</sup> they do not always capture what bothers patients most.<sup>10</sup> Including open-ended questions during patient encounters is an important part of patient care in general,<sup>17</sup> and may be particularly useful for complex phenomena that have a broad spectrum of manifestations, as in the case of PD off periods. However, patients and caregivers may not be able to clearly articulate the meaning of wearing off,<sup>18</sup> and other barriers to communication about off periods are not well understood. Understanding these barriers is important toward educating physicians that care for patients with PD to help them detect this important PD manifestation. To improve the understanding of how patients experience off periods and communicate about them, we undertook an in-depth analysis of how patients describe off periods.

Our results illustrate the rich language individuals with PD use to describe off periods and their creative uses of figurative language to explain their symptoms. However, the findings also highlight the complexity that may exist in

**Table 2** Figurative Language Theme Descriptions, Categories, and Examples Used by Individuals With Parkinson Disease to Describe Off Periods

Theme	Description	N (%) of phrases categorized into specified theme	Examples of words used for each theme
<b>Viscous and textured materials</b>	Any thick or textured substances/materials	20 (18.4)	Mud, quicksand, Jell-O, pudding, glue, cement, rubbery, gummy joints, fuzzy
<b>Chemical and physiologic reactions</b>	Intoxication, chemical influences, and physiologic changes or responses	19 (17.4)	Feel high or drunk, like low blood sugar, like I've had caffeine, feel like I've had too much to drink, adrenaline rush
<b>Miscellaneous objects/animal</b>	Miscellaneous objects used to describe experience	14 (12.8)	Jumping beans, rod, dishrag, fish out of water, ants under skin
<b>Confinement</b>	Being enclosed in or covered by external object or space	13 (11.9)	Armor, cement suit, heavy blanket, caged animal, encased in cement, trapped inside body, wrapped in plastic, straight jacket, sliding down dark tunnel
<b>Dissociation or disconnect</b>	Any disconnect within the body or between the body and external surrounding	12 (11.0)	Jumping out of skin, stupor, outside my body looking at myself, detached from surroundings, catatonic
<b>Fictional character</b>	Characterization of a symptom or phenomena	10 (9.2)	Quazimodo, zombie, Mr. Parkinson, Energizer Bunny, Tin Man
<b>Extreme experience</b>	Specific scenarios detailing an emotionally salient circumstances/action	10 (9.2)	Rock concert, walking on a tightrope, airplane crash, car accident, long foot race, on a rollercoaster, on a cruise ship
<b>Mechanical</b>	Objects powered by mechanics or mechanical part/feature/tool	8 (7.3)	Electrical, wired, wheels, clock, autogiro
<b>Weather/geological event</b>	Weather, geological event, atmospheric conditions	4 (3.7)	Internal earthquake, in a fog/haze
<b>Assault/death</b>	Being physically assaulted or dying	3 (2.8)	Someone choking me, brain is dying, body under attack
<b>Water</b>	Referencing water	3 (2.8)	Feels like walking underwater, wave washing over me

patient-physician communication about off periods: when reviewed by 3 movement disorders experts, the meaning of the figurative language phrases was agreed on in only approximately 40% of cases. Agreement was less likely for phrases that were interpreted as representing nonmotor symptoms.

The themes that emerged in the figurative language phrases represented a range of textures, objects, experiences, or images. Patients described a sense of navigating through, or being encased in, various materials such as mud, rubber, glue, and cement. The references to entrapment recall descriptions from patients with amyotrophic lateral sclerosis.<sup>6</sup> Such phrases were often interpreted by the neurologists as representing motor symptoms such as stiffness and slowness of movement. Another common theme was a sense of being under the influence of exogenous chemicals/intoxicated. The latter phrases were deemed to be referring to nonmotor symptoms by the neurologists. Figurative language may particularly be useful to describe complex, abstract, and/or emotionally laden experiences that are hard to explain with literal language,<sup>1-4</sup> and at the “interface of physical and psychological symptoms.”<sup>19</sup>

Indeed, many of the figurative language phrases used by participants to describe their off periods convey experiences of great difficulty and discomfort.

Movement disorders neurologists that reviewed the figurative language phrases determined that the phrases most often represented motor symptoms, including stiffness, slowness of movement, and tremor. Tremor<sup>20</sup> and bradykinesia<sup>12</sup> are the most commonly reported off symptoms overall, and it is not surprising that these were often selected. However, a variety of nonmotor symptoms were also felt to be represented. This is consistent with an expanding literature on the broad spectrum of both motor and nonmotor symptoms seen in PD.<sup>20-22</sup>

As mentioned, all 3 neurologists agreed on the symptom most likely represented by the figurative language phrase in only 38.5% of instances. Agreement was more likely for motor symptoms; when a figurative language phrase was interpreted as representing a nonmotor symptom, agreement for which specific symptom was represented was low. This lack of agreement on over half of phrases may reflect a combination of factors, including the heterogeneity intrinsic

**Table 3** Examples of Figurative Language Phrases Written by Patients and Symptoms That Each of 3 Neurologists Determined Were Most Likely Represented in Each Phrase

Verbatim phrase ( <b>figurative language in bold</b> )	Most likely symptom represented (no. of neurologists)	Other possible symptoms being represented (no. of neurologists)
I become sluggish and feel that my limbs resist making any movements <b>like being in a straight jacket</b> .	Stiffness (3)	Slowness (1)
My body is fatigued, <b>like it's hit a wall and crashed</b> .	Fatigue (3)	
It feels like I have no medication in me. <b>It is as if the battery in the energizer Bunny just quits:</b> My body slows down and gets stiffer; sometimes it is difficult to breathe and my left hand tremor returns...	Motor weakness (1) Slowness (1) Fatigue (1)	Stiffness (1)
<b>Feel as if I can implode</b> —I hunch over and pull my head into my shoulders. I feel cold and shake.	Flexed/stooped posture (1) Dystonia (1) I really don't know (1)	
Internal tremors <b>like an internal earthquake followed by a switch being turned</b> and my tremors come in my left side predominantly.	Tremor (3)	
Oh yes, the power from one time to another is the power ability to exert missing. Sometimes I have deliberately tried to be angry Or just stop my foot or smash my hand and I cannot. <b>It makes me feel paralyzed or trapped inside my body.</b>	Motor weakness (2) Freezing of gait (1)	Freezing of other body parts (1) Stiffness (1) Slowness (2)
Tightness in jaws and <b>feel like someone is choking me</b> . My nose runs without stopping and I must spit out saliva constantly, especially when I first get up. Though I desperately need the meds, recently, I have been unable to swallow them.	Stiffness (1) Dystonia (1) Trouble swallowing (1)	
Nervous, edgy, muscle tightness, <b>like I am going to crawl out of my skin</b>	Restlessness/akathisia (2) Anxiety/panic (1)	Stiffness (1)
<b>I feel like my body is under attack</b> during off period, the calm feeling that I have is turning into shaking and stiffness.	Tremor (1) Anxiety/panic (1)	Stiffness (1) I really don't know (1)
<b>I feel like a clock that has run completely down</b> and I move all over. I just feel awful.	Motor weakness (1) Slowness (1) Malaise (1)	Fatigue (1)
I think of my off periods as <b>being like a heavy coat or blanket dropping over me, covering my whole body</b> with exhaustion, instability, fogginess, and an overall sick feeling. When it hits, it is difficult for me to do anything other than lying down and waiting for it to pass.	Slowness (2) Motor weakness (1)	Malaise (1) Nausea (1) Fatigue (1) Stiffness (1)
When I am off, <b>my feet feel like they are wrapped in heavy plastic</b> ; they are tingly and numb.	Dysesthesia/paresthesia (1) Stiffness (1) Slowness (1)	Dystonia (1)
I also get sad and discouraged. Sometimes I feel it coming on... <b>like I am sliding down a dark tunnel</b> .	Depression (3)	
I can't pick up my feet. <b>Legs feel rubbery</b> .	Motor weakness (2) Slowness (1)	Stiffness (1) Shuffling gait or festination (1)
It's not that I can't think straight or carry on a conversation, but <b>the "wheels" seem to turn very slowly</b> and I get quiet. I feel vulnerable and depleted, and sometimes anxious.	Bradyphrenia (2) Concentration (1)	Slowness (1)
<b>Like being in jail in my Own body</b> .	Stiffness (2) I really don't know (1)	Slowness (1)

Continued

**Table 3** Examples of Figurative Language Phrases Written by Patients and Symptoms That Each of 3 Neurologists Determined Were Most Likely Represented in Each Phrase (*continued*)

Verbatim phrase (figurative language in bold)	Most likely symptom represented (no. of neurologists)	Other possible symptoms being represented (no. of neurologists)
<b>It's like flying in a plane 30,000 ft. in the air, and all of a sudden, it begins its descent.</b> I feel dejected, rejected, and that my life is not worth living.	Depression (1) Fluctuation (1) Anxiety/panic (1)	

Number in parenthesis indicates the number of neurologists that designated a specific symptom (maximum 3).

to PD,<sup>23</sup> the broad range of ways in which patients experience complex PD manifestations and communicate about them,<sup>24,25</sup> and the inherently subjective nature of interpreting figurative language.<sup>26</sup> These and other factors may lead to misunderstandings in communication about off periods and, in turn, their suboptimal detection<sup>12</sup> and

treatment. These results highlight the importance of active listening and clarifying information during provider-patient communication and add an additional facet to the idea of “shared understanding.”<sup>8,9</sup> Much research has focused on how to improve patient understanding of what physicians are communicating to them. In that context, the use of

**Table 4** Specific Symptoms and Categories of Symptoms Indicated by Neurologist as Most Likely to Be Represented by Figurative Language Phrase and Agreement Among Neurologists

Symptom	Selected by ≥1 neurologist <sup>a</sup>	Category	Frequency <sup>a</sup> (no. of phrases)	Only 1 neurologist <sup>b</sup>	2/3 neurologists <sup>b</sup>	3/3 neurologists <sup>b</sup>	Kappa
<b>Imbalance</b>	9	Motor-gait/balance/truncal	17	7 (41%)	1 (6%)	9 (53%)	0.7503 <sup>c</sup>
Freezing of gait	5						
Retropulsion	0						
Shuffling gait or festination	1						
Flexed/stooped posture	2						
<b>Tremor</b>	16	Motor-other	70	10 (14%)	18 (26%)	42 (60%)	0.6566 <sup>c</sup>
Slowness	29						
Stiffness	29						
Dystonia	2						
Dyskinesia	1						
Motor weakness	15						
Motor fluctuation	7						
Freezing of other body parts	0						
<b>Hypophonia</b>	1	Bulbar/speech	3	1 (50%)	1 (25%)	1 (25%)	0.6604 <sup>c</sup>
Dysarthria	1						
Trouble swallowing	2						
<b>Restlessness/akathisia</b>	12	Sensory	16	9 (56%)	4 (25%)	3 (19%)	0.4568 <sup>c</sup>
Dysesthesia/paresthesia	4						
<b>Concentration</b>	12	Cognitive	17	4 (33%)	5 (42%)	3 (25%)	0.5791 <sup>c</sup>
Memory difficulty	0						
Inattentiveness	0						
Bradyphrenia	1						
Cognitive impairment	4						
<b>Depression</b>	3	Psychiatric	13	5 (38.5%)	3 (23%)	5 (38.5%)	0.6657 <sup>c</sup>
Anxiety/panic	8						
Dissociation	4						
Apathy	0						
<b>Fatigue</b>	7	Fatigue/malaise	10	7 (70%)	1 (10%)	2 (20%)	0.4410 <sup>c</sup>
Malaise	4						
<b>Dizzy/lightheaded</b>	1	Autonomic/GI	1	1 (100%)	0	0	-0.0031
Nausea	0						
<b>I really don't know</b>	19	I really don't know	19	16 (84%)	3 (16%)	0	0.0741

<sup>a</sup> Total number exceeds frequency number because permutations within the same category result in a lower frequency count for categories vs individual symptoms.

<sup>b</sup> Number of phrases and percent of phrases designated by 1, 2, or 3 neurologists as representing the specified category of symptoms is shown.

<sup>c</sup> Inter-rater agreement significantly greater than expected by chance ( $p < 0.05$ ).

**Table 5** Proportion of Phrases for Which Agreement Was Present Among All 3 Neurologists as to the Most Likely Category of Symptoms Being Represented

Symptom category	No. of phrases designated by $\geq 1$ neurologist as representing a symptom belonging to specified category	Proportion achieving agreement (3/3 neurologists)	Motor_other	Motor_gait_trunk	Bulbar_speech	Sensory	Cognitive	Psychiatric	Fatigue_malaise
<b>Motor_other</b>	70	60.0%							
<b>Motor_gait_trunk</b>	17	52.9%	0.596						
<b>Bulbar_speech</b>	3	33.3%	0.358	0.531					
<b>Sensory</b>	16	18.8%	0.003 <sup>a</sup>	0.041 <sup>a</sup>	0.570				
<b>Cognitive</b>	12	25.0%	0.024 <sup>a</sup>	0.132	0.770	0.690			
<b>Psychiatric</b>	13	38.5%	0.150	0.431	0.869	0.238	0.471		
<b>Fatigue_malaise</b>	10	20.0%	0.017 <sup>a</sup>	0.093	0.631	0.937	0.781	0.340	
<b>Autonomic_GI</b>	1	0	0.226	0.303	0.505	0.633	0.569	0.439	0.621
<b>Don't know</b>	19	0	<0.001 <sup>a</sup>	<0.001	0.010 <sup>a</sup>	0.048 <sup>a</sup>	0.022 <sup>a</sup>	0.033 <sup>a</sup>	0.043 <sup>a</sup>

<sup>a</sup> *p* Values reflect significance for test of proportions among pairs of categories.

figurative language by physicians was reported by cancer patients to improve their understanding of health problems and increase their satisfaction.<sup>27</sup> However, the impact of figurative language on the communication of patients with their providers is less well studied. One study in cancer patients indicated that providers may not recognize or respond to patients' use of figurative expression.<sup>28</sup> Our results highlight a simple yet important aspect of patient-physician communication: that physicians should not assume complete or accurate comprehension of what a patient means when they describe their experiences using figurative language that could be interpreted in different ways. Rather, relating to the patient what meaning was taken, and simply asking the patient what they meant in such circumstances, allows the opportunity for further clarification and exploration. These and other active listening techniques<sup>29,30</sup> foster a patient-centered approach that could help enhance patient-physician communication, patient satisfaction, and ultimately may improve patient outcomes.<sup>17,31</sup>

The question that asked participants about their experience during off periods was open-ended and allowed for free-text responses. In this written format, most participants used literal language to describe their experience. However, even in this research setting where figurative language was not specifically elicited, 4% of responses used some form of it. Figurative language may be used more often during verbal communication (such as would occur in the clinic) as compared to written communication.<sup>32</sup> Thus, healthcare

providers will encounter the use of figurative language to describe off periods, whether in clinic or in written text by patients to their healthcare team such as in patient messages sent in the electronic medical record. Awareness of the high frequency of ambiguity in the meaning of figurative language in this context leading to caution against assuming what a patient means without clarifying has the potential to improve communication between healthcare providers and patients with PD.

In our study, a larger proportion of those using figurative language were women. Sex differences in frequency and type of metaphor used has been reported in other patient populations such as those with depression.<sup>33</sup> Additional work to better understand sex or other demographic differences in the type of language used in description of PD experiences also has the potential to enhance patient-physician communication.

The design of this study did not allow for us to ask participants what they meant by the figurative language phrase they used. This is a limitation of this study, and future work will incorporate this critical aspect to better understand the use of figurative language in PD. Other limitations include the relatively high education and low diversity of our sample; this is particularly relevant, given cultural influences on the use of figurative language.<sup>34</sup> Therefore, our results may not be generalizable to the broader PD population.



Individuals with PD use a wide range of figurative language to describe their experience with off periods. An awareness of this, and the potential for even an experienced physician to not grasp the full meaning intended to be relayed by the patient, is an important step toward improving patient-physician communication.

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<b>Briana Edison, MPH</b>	Department of Neurology, University of Pittsburgh, PA	Study design, acquisition, interpretation of data, and review and revision of manuscript
<b>Margaret Daeschler, MA</b>	Georgetown University, Washington, DC	Study design and review and revision of manuscript
<b>Bernadette Siddiqi, MA</b>	The Michael J. Fox Foundation for Parkinson's Research, New York	Review and revision of manuscript
<b>Catherine Kopil, PhD</b>	The Michael J. Fox Foundation for Parkinson's Research, New York	Study design and review and revision of manuscript
<b>Connie Marras, MD, PhD</b>	The Edmond J. Safra Program in Parkinson's disease, Toronto Western Hospital, University of Toronto, Ontario, Canada	Study design, acquisition, interpretation of data, and review and revision of manuscript
<b>Sneha Mantri, MD, MS</b>	Department of Neurology, Duke University, Durham, NC	Study design, acquisition, analysis, interpretation of data, and drafting the work final approval of the version to be published

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## TAKE-HOME POINTS

- Figurative language may particularly be useful to describe complex, abstract, and/or emotionally laden experiences that are hard to explain with literal language; individuals with PD use figurative language to describe their experiences with off periods.
- Neurologists agreed on what symptoms the figurative language phrases were referring to in only a minority of instances.
- To optimize physician-patient communication around off periods, it is important for neurologists who care for patients with PD to be the alert for possible use of figurative language by patients, and to ensure, through active listening and clarifying questions that the meaning intended to be relayed by the patient is understood.

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