# Perspectives on Parkinson's **Disease Medications:** A Qualitative Study of People With Parkinson's Disease

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# **CONCLUSIONS**

- Among people with Parkinson's disease (PwPD), there is genuine uncertainty regarding the effectiveness of PD medications and the side effects they experience.
- High dosing frequency is burdensome, and PwPD desire longer-lasting medications and more therapeutic options to address their unmet needs.
- Results indicate the need for enhanced communication between providers and patients regarding PD medications to discuss experienced side effects and reduce uncertainties around symptom burden.

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**REFERENCES: 1.** Johnsrud et al. *Clin Park Relat Disord.* 2021;5:100109. **2.** Richy et al. *Appl Health Econ Health* Policy. 2013;11:395-406. **3.** Delea et al. CNS Drugs. 2011;25:53-66. **4.** Davis. Mov Disord. 2010;25:474-480. **5.** Tarrants et al. *Am J Geriatr Pharmacother.* 2010;8:374-383. **6.** Kulkarni et al. *Mov Disord.* 2008;23:359-365.

# INTRODUCTION

- Medication regimens to manage the symptoms of Parkinson's disease (PD) are often complicated
- Real-world evidence indicates that adherence to PD medications is suboptimal, with only 33-54% meeting standard adherence thresholds  $(e.g., 80\%)^{1-6}$
- Few studies investigate the factors that inform the impact of PD medication on individuals' lives
- Patient experience data are needed to better understand the patient perspective regarding PD medications and to improve patient care and outcomes

Overall, 52 PwPD participated: 20 in SSIs and 32 in FGs

Participants averaged 71 years of age; 54% were male

• 44% had a recent H&Y score of ≥3

and 8.1 years for FG participants

presented in Table 1

Age (y), mean (range)

Recent H&Y Score, n (%)

Time since diagnosis (y),

Effectiveness

Side effects

Desires

- Timing challenges

Dosage timing, off-times

Therapy advancement, more options

FG, focus group; H&Y, Hoehn & Yahr; SSI, semi-structured interview.

Four primary themes emerged regarding PD medications

Uncertainty about effectiveness, realignment of expectations

• Exemplar quotes are provided for each theme in italics (**Figure 1**)

Tolerating side effects, discerning side effects vs. disease progression

Characteristic

**Sex**, n (%)

Female

1-2.5

3-5

mean (range)

# **OBJECTIVE**

• To explore the thoughts, beliefs, and expectations of people with Parkinson's

**RESULTS** 

disease (PwPD) regarding their PD medications

Self-reported time since PD diagnosis averaged 9.0 years for SSI participants

• The demographic and clinical characteristics of SSI and FG participants are

SSI participants

(n=20)

8 (40.0)

71.7 (48-80)

10 (50.0)

10 (50.0)

9.0 (1-39)

FG participants

(n=32)

16 (50.0)

71.3 (57-86)

19 (59.4)

13 (40.6)

8.1 (2-30)

**Table 1. Participant Demographic and Clinical Information** 

### Figure 1. Patients' Perspectives Regarding PD Medications

**METHODS** 

Inclusion criteria

PD diagnosis

Aged ≥18 years

Fluent in English

interviews (SSIs) and focus groups (FGs)

Duke University – Durham, North Carolina

University of Colorado – Aurora, Colorado

University of Florida – Gainesville, Florida

Recent notation of Hoehn & Yahr (H&Y) score

History of PD medication utilization

Able to consent and participate

- Barrow Neurological Institute - Phoenix, Arizona

Oregon Health & Science University – Portland, Oregon

### **EFFECTIVENESS**

PwPD treated with oral PD medications were recruited to participate in semi-structured

Patients were recruited from 5 large movement disorder clinics in the United States

- I feel different every day. Sometimes I feel like my medicine is not working. Sometimes I feel like it's not working long enough.
- I wonder if I should be feeling more symptom relief than I am currently feeling. I'm not discounting that I'm feeling any symptom relief because I'm definitely feeling the symptom relief, but I do wonder if I should be feeling more.
- I think whether this is the right medication for me, whether I should be taking another one. Those are all things I wonder about. Then it has been tempting to say, "I think I'll go off of it for a while."

PwPD described needing to realign their expectations regarding medication effectiveness.

- were going to stop the tremor and stop the stiffness, and this slow moving ... and they don't do that, not with Parkinson's.
- I expected that the replacement of the dopamine would take care of filling that void and take care of the problem, but that's not the case.
- it has been. I was expecting to take a pill and say, "Oh wow. That made a difference." What was unexpected is I took it and I really did not notice much difference.

# TIMING CHALLENGES

Many PwPD were frustrated with and burdened by their medication regimen frequency.

- I feel like I'm being tied to that pillbox. The other thing too is that with this carbidopa/levodopa you're supposed to take it at least a half hour to an hour away from any meals, and I'm supposed to take it three times a day. Trying to do that and juggle the pill taking with my meals and my schedule with the rest of my life, it's just a pain.
- You would not believe how fast two hours goes. I take my pill, and then two hours later, the alarm goes off again. I'm like, "What? Two hours has gone by? It felt like it was 10 minutes."
- I have to take some medication six times a day and I'm reminded of my Parkinson's six times a day. I would just like for it to not be such an important part of my life.

Some PwPD reported struggles with the return of symptoms before the next medication dose was scheduled. Some took medication in the early morning hours to prevent morning off-times.

- · When it wears off, it is bad. When the medication wears off, I do a stutterstep. I try to take a step and all of a sudden I'm some sort of tap dancer. I have to stop, I have to take a deep breath, I have to deliberately pick up a foot, put it down.
- It appears to me right now that five hours, these five-hour intervals [between doses] are insufficient. I've got to get a dose that's either bigger so it lasts longer, or more frequent
- I also have to take medicine in the middle of the night so I can get up in the morning. I take a pill about 3:00 AM, or something like that, three or four in the morning, then I'm ready to go when I get out of bed, just like normal.

# TIMING **CHALLENGES**

SSIs

FGs

1-hour interviews via telephone

1-hour sessions via Zoom

Conducted between October 2020 and September 2021

SSI and FG transcripts were analyzed using NVivo qualitative data

University of Texas Institutional Review Board approved the study

Conducted between March and April 2022

analysis software (Lumivero, Denver, CO)

### SIDE EFFECTS

**EFFECTIVENESS** 

### **DESIRES**

- then you kind of get used to feeling that way.
- I thought it was something I had to accept, really, the side effects. All of the medications
- side effects. If it's effective, I tolerate the side effects.

PwPD discussed their uncertainty as to whether a symptom they experienced was a medication side effect or a sign of PD progression.

- When I started having extra symptoms, I first believed, "Your disease is just progressing." Then I began to notice what times of the day I was having it, and the more medication I took, the more symptoms I had and it was like, "Wait a minute. Are we sure that that's what it is?"
- It's hard to tell because all these drugs' side effects, all of them have the same symptoms, potential, as what Parkinson's presents with. It's hard to differentiate. Is it a
- How do all these medications work together? I'm on a lot of medication. You don't know whether something is causing the symptoms or whether it's just part of the

PwPD expressed the desire for a curative therapy and more therapy options, including longer-lasting medications.

- Let's have a cure. We've got gene therapies and DNA things that we are using in other areas. I don't think it's a stretch to go that direction.
- I'm in the "go big or go home" camp. Find the cure. Stem cell research has all kinds of possibilities out there.
- I'd like to have medication that would last longer. You wouldn't have to take it four times a day. It would be nice if you could take it once or maybe twice.
- There needs to be some type of injectable or pump or something that is more efficient and continuous than taking a pill that is as effective as the vagaries of the diet that you have that day.
- It would be nice to have a medication that you didn't have to worry about protein ingestion. Because now you have to time taking your medications of when you're eating and what you're eating and calculating all of that.

Many PwPD were unsure if their PD medication regimen is as effective as it can be.

- I would say they don't totally do what I thought they were going to do. I thought they
- I expected to see some impact of the medication more strongly, more dramatically than

### SIDE EFFECTS

Several PwPD reported tolerating PD medication side effects.

- It's better if you take it on an empty stomach, but then you feel queasy all the time and
- I think it goes back to just something that's effective. To me, I'm trading symptoms for

- side effect or is it your disease? ... It's really hard to tell the chicken from the egg for me.

PD, Parkinson's disease; PwPD, people with Parkinson's disease

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