

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

OBJECTIVE

- To explore the thoughts, beliefs, and expectations of people with Parkinson's disease (PwPD) regarding their PD medications

RESULTS

- 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
- Self-reported time since PD diagnosis averaged 9.0 years for SSI participants and 8.1 years for FG participants
- The demographic and clinical characteristics of SSI and FG participants are presented in **Table 1**

Table 1. Participant Demographic and Clinical Information

Characteristic	SSI participants (n=20)	FG participants (n=32)
Sex, n (%)		
Female	8 (40.0)	16 (50.0)
Age (y), mean (range)	71.7 (48-80)	71.3 (57-86)
Recent H&Y Score, n (%)		
1-2.5	10 (50.0)	19 (59.4)
3-5	10 (50.0)	13 (40.6)
Time since diagnosis (y), mean (range)	9.0 (1-39)	8.1 (2-30)

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

- Four primary themes emerged regarding PD medications
 - Effectiveness**
 - Uncertainty about effectiveness, realignment of expectations
 - Side effects**
 - Tolerating side effects, discerning side effects vs. disease progression
 - Timing challenges**
 - Dosage timing, off-times
 - Desires**
 - Therapy advancement, more options

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

METHODS

- PwPD treated with oral PD medications were recruited to participate in semi-structured interviews (SSIs) and focus groups (FGs)
- Patients were recruited from 5 large movement disorder clinics in the United States
 - Barrow Neurological Institute – Phoenix, Arizona
 - Duke University – Durham, North Carolina
 - University of Colorado – Aurora, Colorado
 - University of Florida – Gainesville, Florida
 - Oregon Health & Science University – Portland, Oregon
- Inclusion criteria
 - PD diagnosis
 - History of PD medication utilization
 - Recent notation of Hoehn & Yahr (H&Y) score
 - Aged ≥ 18 years
 - Fluent in English
 - Able to consent and participate

- SSIs
 - 1-hour interviews via telephone
 - Conducted between October 2020 and September 2021
- FGs
 - 1-hour sessions via Zoom
 - Conducted between March and April 2022
- SSI and FG transcripts were analyzed using NVivo qualitative data analysis software (Lumivero, Denver, CO)
- University of Texas Institutional Review Board approved the study

Figure 1. Patients' Perspectives Regarding PD Medications

