



Positively Prurient. Users Describe *Macuna pruriens* More Favorably Negatively than Levodopa in an Online Forum Devoted to Parkinson's

Callie Winters, MD, Michael Chary, MD, PhD

Department of Emergency Medicine, New York Presbyterian Queens, Department of Emergency Medicine, Weill Cornell Medicine

Background

- Parkinson's Disease results from loss of dopamine-producing neurons. The main treatment is levodopa (L-DOPA).
- Approximately 80% of Parkinson's patients use herbal and dietary supplements (HDS) most commonly *Mucuna pruriens* (MP), which contains, 2-40% L-DOPA.
- HDS use may interfere with physician treatment
- Patients rarely disclose HDS use to physicians but frequently discuss HDS use in online forums.
- We have previously established online forums as a source of valid toxicological information.
- Analysis of discussions in online forums may identify reasons for HDS use and non-adherence to standard therapy

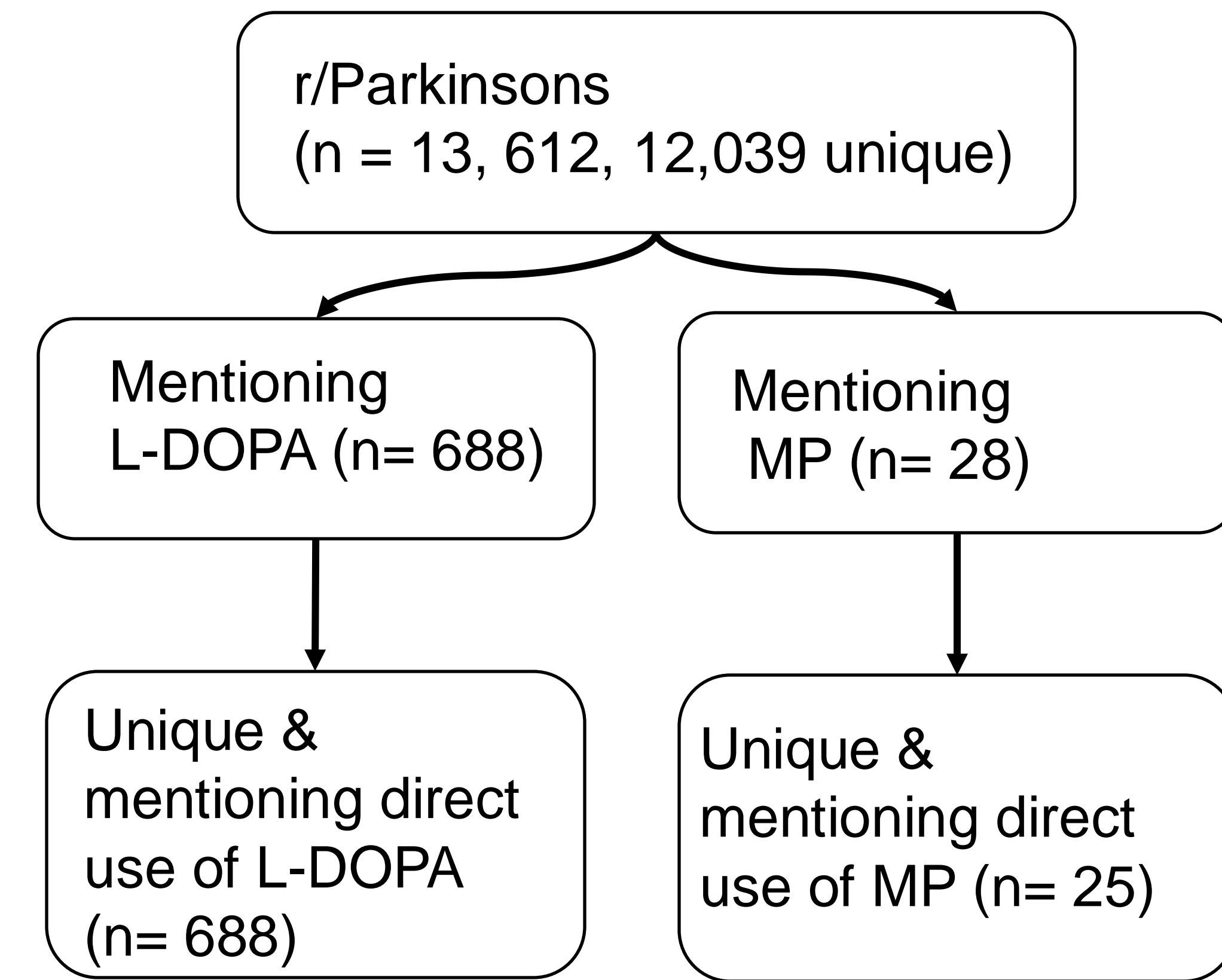


Figure 1. Inclusion of Comments for Analysis. MP, *Macuna pruriens*. L-DOPA, any levodopa containing pharmaceutical.

Results (Quantitative)

		Sentiment		
		Positive	Negative	Neutral
Substance	MP	5	7	13
	L-DOPA	258	85	345

Figure 2. Users describe *Macuna pruriens* as favorably as medications that contain L-DOPA.

		L-DOPA Dose
MP	20 (8-150) mg	
Pharma	154 (3-380) mg	

Figure 3. Users describe taking less L-DOPA from *M. pruriens* (MP) than pharmaceutical forms (pharma). Calculated daily amount assuming 4% L-DOPA and twice daily dosing unless otherwise specified

Conclusions

- **Users discuss the benefits, risks, and motivations for using MP in online forums.**
- Users turn to *Macuna*:
 - To self-diagnose or self-treat while waiting to see a Parkinson's specialist
 - From dissatisfaction with pharmaceutical levodopa
 - To supplement their pharmaceutical regimens for better control of symptoms
- **The doses discussed of L-DOPA via MP are generally lower than L-DOPA via pharmaceuticals**

Research Question

1. Is *Macuna pruriens* perceived as more effective or tolerable than pharmaceutical L-DOPA?
2. What circumstances that lead people to use MP-containing supplements?

Methods

Data Acquisition. Author MC wrote custom software in R and Python to extract all comments and posts from the subreddit r/Parkinson's from the start of the subreddit to January 2025. The software is available on GitHub at LINK.

Data Preprocessing. We manually **standardized** comments, replacing brand names with generic names, expanded abbreviations, and corrected misspellings. We counted multiple identical posts by one user as one comment.

Data Analysis.
Perception. We manually **labelled** each comment for (1) mentioning MP, (2) mentioning L-DOPA, (3) if the experience was positive, negative, neither, or both.

Thematic Analysis. We conducted two rounds of qualitative analysis to identify themes in the post and then group post and comments by theme.

Results (Qualitative)

Theme

Examples

Lack of Access to Care

- "I'm self-treating due to a combo of long waitlists and honestly feeling completely failed by my doctors, yay HMOs. As @ParkieDude mentioned, mucuna pruriens is very helpful."
- "For me, medicine that relieves my symptoms is typically a **combination** of a Mucuna product plus either carbidopa alone or CL (sinemet) - either in very small amounts, along with the Mucuna product."
- "I took Mucuna pruriens for about 3 months **prior to my formal diagnosis**, when I suspected I might have PD."
- Multiple users described difficulty obtaining insurance coverage for or affording brand-name or specific formulations of levodopa medications that they preferred over the generic

Concern over lack of quality control for supplement

- "Problem is that because it is not an FDA approved drug, **there's no oversight** on quantity being the same from pill to pill."
- "Generic C/L is inexpensive, you can measure the dose better, **why mess with mucuna pruriens?**"
- Multiple users cited a lack of regulation and oversight, as well as risk of adulterants and overdosing when combining *Macuna* supplements with pharmaceutical levodopa

Nonspecific Discussion

- "Has he ever tried Mucuna Pruiens? And give him 100 mg of 5-HTP before bed. Also there's a probiotic that specifically works in the brain that stops the buildup of the protein called alpha-synuclein which causes the loss of dopamine cells in the brain. And the particular probiotic is called Bacillus Subtillis PNX21 and it's contained in a product called BIO-KULT..."
- "Not an alternative, since it's the first one ever, works better then Levodopa: mucuna."

Positive Experiences

- "I recently bought and began taking a supplement called mucuna pruriens, which is 40% L-DOPA, and a lot of my symptoms are responding to it. I haven't had such clarity of mind in years. Not even my stimulants clear my mind to such a degree."

Negative Experiences

- Inadequate response to medication (MP >> L-DOPA)
- Side effects (nausea, dyskinesia*, sleepiness) (L-DOPA)
- Cost and logistic difficulty obtaining medication (L-DOPA)

Table 1. Users describe turning to *M. pruriens* (MP) because of barriers to standard of care or side-effects of standard of care but are frustrated with MP's lack of efficacy. Quotes indicate verbatim posts. C/L, CL, sinemet refer to Sinemet (carbidopa/levodopa). @ indicates username, e.g. @ParkieDude, PD, Parkinson's Disease.

Limitations

- No verification of users, diagnoses, or dosing.
- Combined all pharmaceutical formulations, some of which have other active components
- Evaluation of comments as positive or negative is subjective
- Considered daily dosing but not intraday fluctuations.

References

1. Zafar S, Yaddanapudi SS. Parkinson Disease. [Updated 2023 Aug 7]. In: StatPearls [Internet]. Treasure Island (FL): StatPearls Publishing; 2025 Jan-. Available from: <https://www.ncbi.nlm.nih.gov/books/NBK470193/>
2. Gandhi KR, Saadabadi A. Levodopa (L-Dopa) [Updated 2023 Apr 17]. In: StatPearls [Internet]. Treasure Island (FL): StatPearls Publishing; 2025 Jan-. Available from: <https://www.ncbi.nlm.nih.gov/books/NBK482140/>
3. Rabin ML, Stevens-Haas C, Havrilla E, Rosenstein A, Toffey B, Devi T, Earnhardt MC, Kurlan R. Complementary Therapies for Parkinson's Disease: What's Promoted, Rationale, Potential Risks and Benefits. *Mov Disord Clin Pract.* 2015 Jun 29;2(3):205-212. doi: 10.1002/mdc3.12170. PMID: 30363487; PMCID: PMC6178661.
4. Chary M, Yi D, Manini AF. Candyflipping and Other Combinations: Identifying Drug-Drug Combinations from an Online Forum. *Front Psychiatry.* 2018 Apr 30;9:135. doi: 10.3389/fpsy.2018.00135. PMID: 29760666; PMCID: PMC5936764.

Acknowledgements

The Investigators would like to acknowledge the people with Parkinson's and their caregivers who posted on r/Parkinsons.