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Attitudes and beliefs towards medication burden and deprescribing in Parkinson disease

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Abstract

Background Deprescribing of potentially inappropriate medications is recommended for older adults and may improve health outcomes and quality of life in persons living with Parkinson disease (PD). Patient attitudes, beliefs, and preferences play a crucial role in the success of deprescribing interventions. We aimed to examine the attitudes and beliefs about medication burden and deprescribing among persons living with PD.

Methods We administered a survey to participants of Fox Insight, a prospective longitudinal study of persons living with PD. The survey included the revised Patients' Attitudes Towards Deprescribing (rPATD) questionnaire and additional questions about adverse drug effects. We used logistic regression models to explore potential predictors of treatment dissatisfaction and willingness to deprescribe.

Results Of the 4945 rPATD respondents, 31.6% were dissatisfied with their current medications, and 87.1% would be willing to deprescribe medications. Male sex was associated with a greater willingness to deprescribe (adjusted odds ratio [aOR] 1.62, 95% confidence interval [CI] 1.37–1.93). A greater belief that the medication burden was high or that some medications were inappropriate was associated with treatment dissatisfaction (aORs 3.74, 95% CI 3.26–4.29 and 5.61, 95% CI 4.85–6.50), and more willingness to deprescribe (aORs 1.74, 95% CI 1.47–2.06 and 2.87, 95% CI 2.41–3.42). Cognitive impairment was the adverse drug effect participants were most concerned about when prescribed new medications to treat nonmotor symptoms.

Conclusions Persons with PD are often dissatisfied with their overall medication load and are open to deprescribing. Medications that are associated with cognitive impairment might be prioritized targets for deprescribing interventions in this population.

Keywords Parkinson disease, Satisfaction with treatment, Willingness to deprescribe, Medication discontinuation, Potentially inappropriate medication, Deprescribing

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Background

Potentially inappropriate medications (PIMs) are medications with therapeutic alternatives that have been found to have a considerably high risk-to-benefit ratio when used in the older adult population [1]. We and others have previously reported that PIM use is unacceptably high among older adults living with Parkinson disease (PD), ranging from 35% for any PIM [2, 3] to 45% for PIMs that may impair cognitive function in PD patients with dementia [4]. PIMs that block cholinergic transmission may be particularly troublesome in persons with PD (a disease characterized as having cholinergic dysfunction) due to their association with cognitive dysfunction [5] and when used chronically, dementia diagnosis [6–9].

Comprehensive medication review and deprescribing (i.e., tapering, stopping, discontinuing, or withdrawing PIMs or medications with no clear indication or benefits) by a healthcare professional can reduce unnecessary polypharmacy, prevent medication-related falls and cognitive impairment, and improve treatment outcomes [10]. However, deprescribing also requires the active involvement of patients and care partners, and shared decision-making alongside their healthcare providers [11]. The design of effective safety interventions for persons living with PD requires knowledge of patients' attitudes towards deprescribing, treatment satisfaction, and motivators of each [10]. In response to this knowledge gap, we administered a survey to the participants of Fox Insight, a large prospective longitudinal study of persons living with PD [12]. Using previously validated instruments in the older adult population [13, 14], we captured Fox Insight participants' perception of medication burden, satisfaction with the current medication regimen, and their attitudes and beliefs about deprescribing. We also used available demographic and PD symptom data to examine whether individual or clinical factors were associated with treatment satisfaction or willingness to deprescribe. For this initial study, our goal was to determine whether there is a general interest in medication safety and deprescribing among individuals with PD, laying the groundwork for future intervention studies targeting specific harmful or unnecessary medications. Finally, using a series of risk–benefit scenarios similar to those used in medical decision-making discussions, we explored what potential medication-exposure-related outcomes the people in our sample considered important and would most like to avoid when starting a new treatment for common PD nonmotor symptoms.

Methods

Ethics approval and consent to participate

The Institutional Review Board (IRB) of the University of Pennsylvania approved this survey (protocol #833498). The New England IRB approved the Fox Insight study. All Fox Insight participants gave informed consent, and if unable, a legal guardian gave consent by proxy at enrollment.

Data source and study participants

Fox Insight is an online longitudinal health survey of over 35,000 international self-identified participants with PD administered by the Michael J. Fox Foundation. Voluntary participants receive screening questionnaires and patient-reported outcome assessments every 90 days; new questionnaires may be added during their participation in the study. The objective of the Fox Insight study is to collect self-reported health information indefinitely from participants. Data collected were de-identified and stored in the Fox Insight data repository to be made available to qualified researchers [12]. On March 16, 2022, a survey developed by the study team was sent to all active Fox Insight participants. Responses were collected through March 15, 2023, and merged with existing Fox Insight data for analysis.

Survey questionnaire and data

Participants received an adaptation of the revised Patients' Attitudes towards Deprescribing (rPATD) questionnaire (Supplementary Table 1) [13, 14]. The rPATD questionnaire assesses patients' agreement with two global questions: "Overall, I am satisfied with my current medicines" and "If my doctor said it was possible, I would be willing to stop one or more of my regular medicines," and probes patients' attitudes and beliefs with additional questions grouped into four factors: medication burden, medication appropriateness, concerns about stopping medications, and involvement in treatment decision-making. The rPATD was followed by a series of risk–benefit scenarios for the treatment of nonmotor symptoms known to be common in PD. Respondents were asked to choose from a list of the symptoms they would most like to avoid as an adverse effect for a new treatment of 1) urinary dysfunction 2) hallucinations and 3) a mood disorder. Additionally, those who were taking medications for PD or PD parkinsonism were also asked about their attitudes related to PD medications and PD symptom management. Survey respondents' demographic (e.g., age, sex, education level, income level) and clinical information (e.g., self-reported motor and nonmotor symptoms) were extracted from the Fox Insight main database (Supplementary Table 2).

Statistical analysis

For each factor in the rPATD, we calculated an individual's factor score by summing their responses to each item and dividing by the number of questions within

the factor, then categorized the result as low or high relative to the sample median [15]. Responses to the two global questions were dichotomized as "agree" ("strongly agree" or "agree") and "disagree" ("neutral," "disagree," "strongly disagree," and "prefer not to answer") for analysis purposes [15]. Logistic regression models were used to explore whether age, sex, number of reported motor symptoms (categorized into quartiles among respondents), and number of reported cognitive symptoms were associated with medication dissatisfaction and willingness to deprescribe. A second set of logistic regression models was built to determine whether medication dissatisfaction and willingness to deprescribe were associated with respondents' beliefs about medication burden, medication appropriateness, concerns about stopping medications, or involvement in treatment decision-making beliefs, adjusting for age and sex. Data was analyzed using SAS v9.4 (Cary, North Carolina, USA), with an alpha level of 0.05.

Results

Among 5015 Fox Insight participants with PD who responded to the survey, 4945 completed the rPATD questionnaire. About 97% of respondents indicated that they answered this survey themselves, while 1–2% responded that either their caregivers, or both themselves and their caregivers were filling out the questionnaire. Characteristics of the people who fully answered the rPATD questionnaire are shown in Table 1; these respondents identified most often as white and have educational achievement and income levels that exceeded the norms for the U.S. adult population [16]. On average, respondents reported 2.94 ± 2.82 out of 13 motor symptoms and 11.12 ± 5.12 out of 30 nonmotor symptoms. Trouble with handwriting was the most frequently reported motor symptom (41.3%) and chewing/swallowing difficulty was the least common (8.5%). Nonmotor symptoms were much more frequent, particularly nonmotor symptoms that we assessed in our risk–benefit scenarios—87.9% had difficulty urinating, 41.6% had anxiety, 55.8% had depressed mood, and 13.5% had hallucinations. Cognitive and sleep symptoms were also common (64.8% and 88.1%, respectively).

Figure 1 displays the distributions of responses to factor and global questions of the rPATD questionnaire. Overall, 31.6% of respondents were dissatisfied with their current medications, and 87.1% were willing to deprescribe medications if recommended by a physician. Respondents to the rPATD questionnaire generally found their medications to be burdensome (79.5% agreed with 1 + burden statements), potentially inappropriate (72.7% agreed with 1 + inappropriateness statements), had concerns about stopping medications (75.2% agreed with 1 + stopping concern statement) and had a high preference for being involved in medication decision-making (99.8% agreed with 1 + involvement statement).

Table 2 displays the associations between demographic factors, selected clinical symptoms, and the likelihood of reporting dissatisfaction with medications or willingness to deprescribe. Male sex was associated with willingness to deprescribe (adjusted odds ratio [aOR] 1.62, 95% confidence interval [CI] 1.37–1.93) but not with dissatisfaction with current medications (aOR 0.96, 95% CI 0.85–1.09) as compared to female sex. Increasing motor and nonmotor symptom severity was associated with medication dissatisfaction but not with willingness to deprescribe. Respondents who reported 1 + cognitive, mood, sleep, or autonomic symptoms were more dissatisfied with their current medications than those who reported no symptoms (aORs ranged from 1.38 to 1.97). Similarly, people who reported a greater number of motor symptoms in the past week or nonmotor symptoms in the past month were more dissatisfied with their current medications compared to people who reported the least symptoms (aORs ranged from 1.21 to 1.95 for motor symptoms, and from 1.32 to 2.21 for nonmotor symptoms).

A reported high level of involvement in treatment decision-making was inversely associated with medication dissatisfaction (aOR 0.69, 95% CI 0.61–0.78), whereas a greater belief that medication burden was high (aOR 3.74, 95% CI 3.26–4.29) or that some medications were inappropriate (aOR 5.61, 95% CI 4.85–6.50) were also associated with increased odds of dissatisfaction with current medications (Table 3). On the other hand, greater perceived burden of medications (aOR 1.74, 95% CI 1.47–2.06) or perceived inappropriateness of medications (aOR 2.87, 95% CI 2.41–3.42), as well as more involvement in treatment decision-making (aOR 1.20, 95% CI 1.01–1.42) were associated with more willingness to deprescribe, contrary to greater concern about discontinuing medications (aOR 0.44, 95% CI 0.36–0.52).

When considering a new medication for common nonmotor symptoms, including urinary problems, mood symptoms, or hallucinations, respondents expressed the strongest preference to avoid adverse effects related to new or worsened memory or thinking (Supplementary Figs. 1–3). Respondents also expressed a desire to avoid a new or worsened inability to walk, falls when getting a new medication for mood or urinary problems, and new or worsening tremor or other PD motor symptoms when getting a new medication for mood or hallucination problems. Additionally, when initiating a new medication for urinary problems, people were also concerned about constipation (33.3%), and when initiating a new

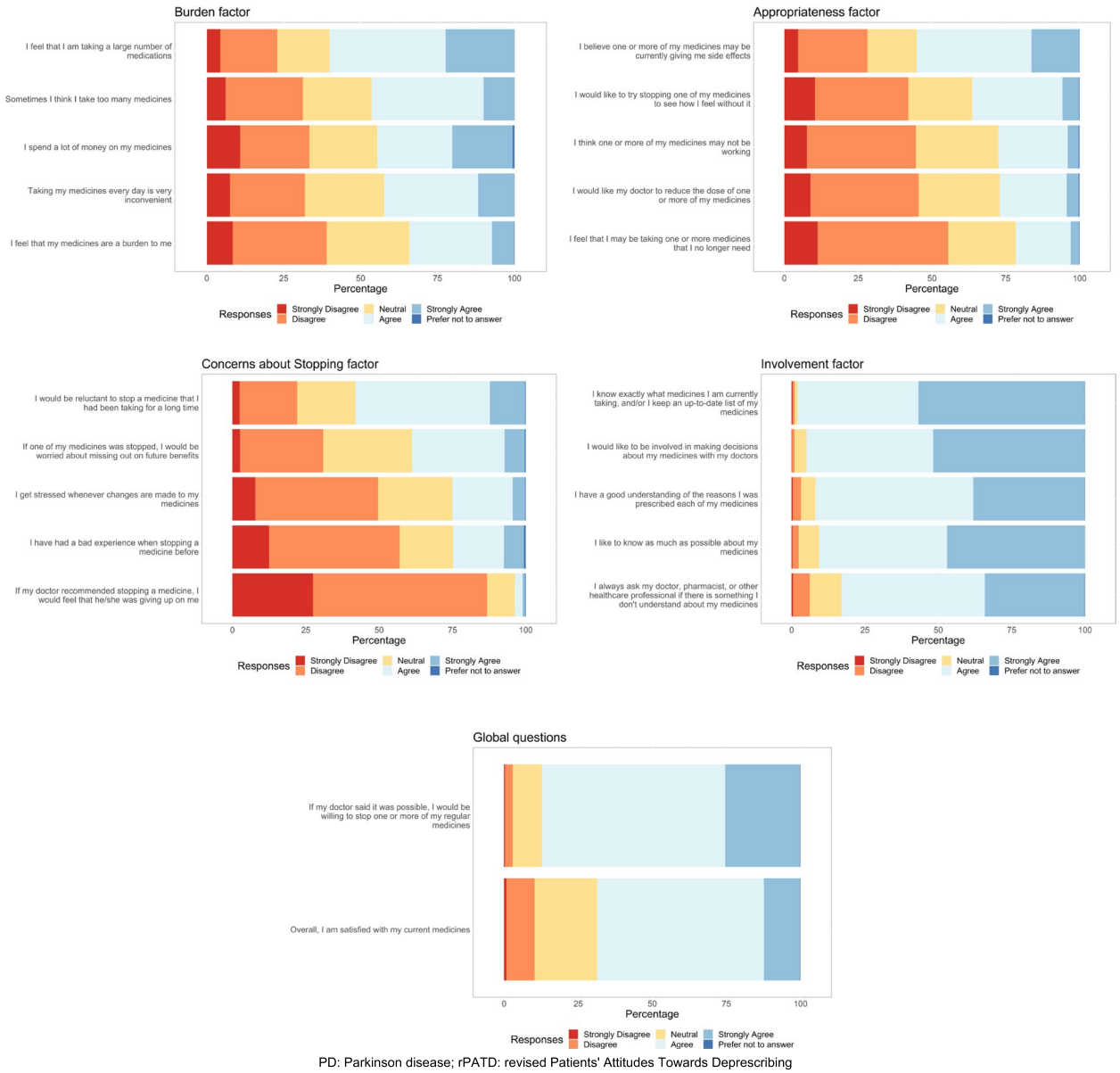
Table 1 Characteristics of rPATD respondents with PD ($n = 4945$)

Characteristics	
Age in years, mean ± SD	68.48 ± 8.54
Age categories, n (%)	
18 to < 65 years	1531 (31.0%)
65 to < 75 years	2302 (46.5%)
> 75 years	1112 (22.5%)
Sex, n (%)	
Female	2582 (52.2%)
Male	2363 (47.8%)
Race, n (%)	
White	4829 (97.6%)
Non-White	116 (2.4%)
Education levels, n (%)	
Less than high school	39 (0.8%)
High school/some college	1039 (21.0%)
Bachelor/associate degree	1903 (38.5%)
Master/professional/doctoral degree	1964 (39.7%)
Income categories, n (%)	
< $20,000 to $49,000	872 (17.6%)
$50,000 to $99,999	1540 (31.1%)
More than $100,000	1603 (32.4%)
Prefer not to answer	737 (14.9%)
Reported motor symptoms (out of 13),[a] mean ± SD	2.94 ± 2.82
Tremor, n (%)	1652 (34.0%)
Freezing of gait, n (%)	661(13.6%)
Walking and balance trouble, n (%)	1267 (26.1%)
Slowness/trouble with ADLs (i.e., eating, dressing or hygiene), n (%)	1106 (23.0%)
Slowness/trouble with hobbies, n (%)	1495 (30.8%)
Speech trouble, n (%)	1563 (32.2%)
Saliva trouble, n (%)	1780 (36.7%)
Chewing/swallowing trouble, n (%)	411 (8.5%)
Handwriting trouble, n (%)	2004 (41.3%)
Slowness/difficulty position changes, n (%)	594 (12.2%)
Reported nonmotor symptoms (out of 30),[b] mean ± SD	11.12 ± 5.12
Cognitive symptoms (i.e., attention/concentration, forgetfulness, hallucination, delusion), n (%)	3165 (64.8%)
Neuropsychiatric symptoms (i.e., anxiety, depression, apathy), n (%)	3447 (70.6%)
Sleep symptoms (i.e., daytime sleepiness, insomnia, dream disturbance, RLS), n (%)	4298 (88.1%)
Autonomic symptoms (i.e., bowel, bladder, orthostatic, sweating), n (%)	4683 (95.9%)
Smell/taste trouble, n (%)	1218 (24.9%)
Pain, n (%)	2113 (43.3%)
Nausea/vomiting, n (%)	1045 (21.4%)
Intimacy trouble, n (%)	2181 (44.7%)
Falls, n (%)	1147 (23.5%)
Weight loss, n (%)	590 (12.1%)
Other troubles (i.e., saliva, swallowing, swelling), n (%)	3039 (62.2%)
Double vision, n (%)	1064 (21.8%)

ADL Activity of daily living, *PD* Parkinson disease, *RLS* Restless leg syndrome, *rPATD* Revised Patients' Attitudes Towards Deprescribing, *SD* Standard deviation

[a] 1.8% of sample did not provided answers to motor symptom related questions

[b] 1.2–1.3% of sample did not provided answers to nonmotor symptom related questions



PD: Parkinson disease; rPATD: revised Patients' Attitudes Towards Deprescribing

Fig. 1 Distributions of answers to rPATD questions among respondents with PD. PD: Parkinson disease; rPATD: revised Patients' Attitudes Towards Deprescribing

medication for hallucination, they were concerned about orthostatic hypotension (34.1%).

Attitudes towards PD medications and PD symptom management among 4775 people who were taking medications for PD or PD parkinsonism in our sample are shown in Supplementary Table 3. In this particular sample, participants generally had a positive view of their PD medications and expressed confidence and trust in their PD specialists. Even though almost half of the respondents (49.5%) believe that one or more of their PD medications might be giving them adverse effects, only 23% and 18.6% expressed that they would like to try stopping their PD medications and reducing their doses, respectively. The majority of people highly prioritized PD motor and nonmotor symptom management.

Discussion

In this study of attitudes towards deprescribing, we found that persons living with PD participating in a longitudinal study were commonly dissatisfied with their current overall pharmacotherapy, and the majority were willing to discontinue one or more chronic medications

Table 2 Demographic and clinical characteristics associated with dissatisfaction with current medications and willingness to deprescribe among rPATD respondents with PD ($n=4945$)

Characteristics		Dissatisfaction With Medications		Willingness to Deprescribe	
		OR (95% CI)[¶]	Adjusted OR (95% CI)[¶]	OR (95% CI)[¶]	Adjusted OR (95% CI)[¶]
Age		**0.99 (0.98–1.00)**	**0.99 (0.98–1.00)**[a]	1.00 (0.99–1.01)	1.00 (0.99–1.01)[a]
Male sex (vs. female)		0.95 (0.85–1.07)	0.96 (0.85–1.09)[b]	**1.62 (1.37–1.92)**	**1.62 (1.37–1.93)[b]**
Motor/Nonmotor symptoms					
Freezing of gait (yes vs. no)		**1.39 (1.18–1.65)**	**1.42 (1.20–1.69)[c]**	0.86 (0.68–1.09)	0.83 (0.65–1.05)[c]
1 + Cognitive symptom (yes vs. no)		**1.38 (1.21–1.57)**	**1.38 (1.22–1.58)[c]**	1.04 (0.87–1.23)	1.01 (0.85–1.21)[c]
1 + Mood symptom (yes vs. no)		**1.69 (1.47–1.94)**	**1.66 (1.44–1.92)[c]**	0.96 (0.80–1.16)	1.01 (0.84–1.22)[c]
1 + Sleep symptom (yes vs. no)		**1.47 (1.21–1.80)**	**1.45 (1.19–1.77)[c]**	1.18 (0.92–1.51)	1.24 (0.96–1.59)[c]
1 + Autonomic symptom (yes vs. no)		**1.87 (1.31–2.66)**	**1.97 (1.38–2.80)[c]**	1.06 (0.70–1.61)	1.08 (0.71–1.64)[c]
Pain (yes vs. no)		**1.57 (1.39–1.77)**	**1.54 (1.36–1.74)[c]**	1.09 (0.92–1.29)	1.14 (0.96–1.35)[c]
Nausea/vomiting (yes vs. no)		**1.71 (1.48–1.97)**	**1.68 (1.45–1.94)[c]**	1.00 (0.81–1.22)	1.09 (0.89–1.34)[c]
Quartile, self-reported motor symptoms in the past week[†]	2nd vs. 1st	**1.21 (1.00–1.45)**	**1.21 (1.01–1.46)[c]**	0.92 (0.72–1.18)	0.90 (0.70–1.15)[c]
	3rd vs. 1st	**1.58 (1.34–1.87)**	**1.62 (1.37–1.92)[c]**	0.89 (0.71–1.12)	0.84 (0.67–1.06)[c]
	4th vs. 1st	**1.88 (1.61–2.20)**	**1.95 (1.67–2.28)[c]**	0.87 (0.70–1.08)	0.83 (0.66–1.03)[c]
Quartile, self-reported nonmotor symptoms in the past month[‡]	2nd vs. 1st	**1.32 (1.10–1.57)**	**1.32 (1.11–1.57)[c]**	1.15 (0.92–1.44)	1.16 (0.93–1.45)[c]
	3rd vs. 1st	**1.88 (1.56–2.26)**	**1.89 (1.57–2.27)[c]**	1.13 (0.89–1.44)	1.14 (0.89–1.45)[c]
	4th vs. 1st	**2.23 (1.88–2.64)**	**2.21 (1.86–2.63)[c]**	1.25 (1.00–1.58)	1.24 (0.98–1.56)[c]

CI Confidence interval, *PD* Parkinson disease, *OR* Odds ratio, *rPATD* revised Patients' Attitudes Towards Deprescribing

[†] Calculated by summing the reported number of motor symptoms experienced in the last week (quartile 1 = 0–1, quartile 2 = 2, quartile 3 = 3–4, quartile 4 = 5 +)

[‡] Calculated by summing the reported number of nonmotor symptoms experienced in the last month (quartile 1 = 0–7, quartile 2 = 8–11, quartile 3 = 12–14, quartile 4 = 15 +)

[¶] Bolded values indicate statistical significance

[a] Adjusted for sex; [b]Adjusted for age; [c]Adjusted for age and sex

Table 3 Beliefs and attitudes associated with dissatisfaction with current medications and willingness to deprescribe among rPATD respondents with PD ($n=4945$)

Medication Beliefs/Attitudes Domains	Dissatisfaction With Medications		Willingness to Deprescribe	
	OR (95% CI)[¶]	Adjusted OR (95% CI)[¶]	OR (95% CI)[¶]	Adjusted OR (95% CI)[¶]
Level of perceived burden of current medication regimen (high vs. low)	**3.76 (3.28–4.31)**	**3.74 (3.26–4.29)[a]**	**1.74 (1.47–2.06)**	**1.74 (1.47–2.06)[a]**
Level of belief that some current medications are inappropriate (high vs. low)	**5.38 (4.65–6.22)**	**5.61 (4.85–6.50)[a]**	**2.95 (2.47–3.51)**	**2.87 (2.41–3.42)[a]**
Level of concern about discontinuing medications (high vs. low)	1.06 (0.94–1.19)	1.05 (0.93–1.18)[a]	**0.44 (0.36–0.52)**	**0.44 (0.36–0.52)[a]**
Level of involvement in treatment decisions (high vs. low)	**0.71 (0.63–0.80)**	**0.69 (0.61–0.78)[a]**	1.15 (0.98–1.36)	**1.20 (1.01–1.42)[a]**

CI Confidence interval, *PD* Parkinson disease, *OR* Odds ratio, *rPATD* revised Patients' Attitudes Towards Deprescribing

[¶] Bolded values indicate statistical significance

[a] Adjusted for age and sex

if advised by their physicians to do so. Our findings are similar to rPATD studies of deprescribing attitudes in the general older adult population, which ranged from 83.0% to 93.4% for willingness to deprescribe [13–15, 17–19], including a sample of older adults with dementia (87.0%) [20]. However, our sample expressed lower satisfaction with their current treatment as compared to the studies of the general older adult population (with satisfaction rates ranging from 79.2% to 92.1%) [15, 18, 19, 21, 22]. Considering that most persons in our sample receive comprehensive specialty care for PD, this difference in satisfaction may underscore the complexity of PD itself, which requires the management of both motor and nonmotor symptoms, and is frequently plagued by motor

fluctuations despite best management. Additionally, PD is typically accompanied by other chronic comorbidities common in older age, which further complicate overall treatment optimization.

We found that male sex was associated with willingness to deprescribe, which has not been consistently observed in other studies of older adults using the rPATD [15, 19, 23]. While Peirera and colleagues found that female sex was associated with more willingness to deprescribe [23], others observed no association between gender and willingness to deprescribe in their study samples [15, 19] even when there was an association between female sex and satisfaction with current medications [15]. Over the past decade, the amount of evidence supporting the notion that there are sex differences in PD symptoms and outcomes [24, 25] involving biological (comorbid disease, symptoms burden), sociocultural (e.g., caregiving norms, tolerance for disability), and healthcare factors (e.g., clinician bias, specialty care access) has grown considerably. Women with PD underutilize treatment resources and research opportunities, likely due in part to having less social support, difficulty accessing specialty care, as well as competing demands and expectations to be a caregiver to others [24, 25], etc. Our data support the growing understanding that it is necessary to tailor interventions and care models to reduce known sex disparities in PD.

The American Geriatrics Society Beers Criteria® for PIM use in older adults offers multiple candidates for deprescribing relevant to the older adult population [1], among which anticholinergics are perhaps the most relevant for persons living with PD. Besides anticholinergic antiparkinsonian medications, which most oftentimes have clear indications for motor symptom management, participants with PD are commonly prescribed anticholinergics for the treatment of urinary dysfunction, mood symptoms, or psychosis [26]. Previous studies have shown associations between anticholinergic use and increased risk of cognitive decline or dementia in the older adult population [27–30], and several studies also reported a similar negative impact on cognition among PD patients taking drugs with anticholinergic properties [6–9], possibly due to compounding effects with the existing cholinergic deficits in this population [26]. Our findings suggest that persons living with PD are greatly concerned about adverse effects related to cognitive impairment; thus, a deprescribing intervention tailored to avoid cognitive decline would likely be highly prioritized by this patient population.

On the other hand, our findings also suggested that individuals taking medications for PD or PD parkinsonism generally had a positive attitude regarding these medications and would be less open to deprescribing or reducing the doses of these medications despite experiencing potential adverse effects from them, as managing both motor and nonmotor symptoms was greatly important to them. Therefore, it is essential to design future deprescribing interventions for this patient population with their priorities in mind, recognizing that there may be barriers to initiating conversations about deprescribing medications used for managing nonmotor symptoms, even though they might be inappropriate and harmful.

Strengths of our study include the use of a previously validated instrument in a large sample of highly engaged individuals living with PD, and our ability to link new data to existing information about PD motor and nonmotor symptoms because of the longitudinal nature of the Fox insight study. Our study is unique because it is patient-centered rather than prescriber-centered, recognizing that deprescribing interventions will not be effective if solely driven by physicians. Our findings offer a critical perspective from a large sample of participants with PD and demonstrate that they are also interested in discussions about medication safety and potentially deprescribing if recommended by their physicians. However, our study also faced challenges of generalizability due to the under-representation of persons from rural areas, persons with population average educational achievement and socioeconomic status, women, and persons from racialized and minoritized populations. Due to the online and voluntary nature of the Fox Insight study, the study sample may include respondents who lack adequate cognitive function or sufficient insight to accurately complete the questionnaires, potentially affecting the reliability and interpretability of our findings. Moreover, the rPATD does not assess other potential factors that may influence deprescribing attitudes, such as healthcare accessibility, the physician/pharmacist-patient relationship, and care partner presence/availability. These factors may be important enablers or barriers in implementing a successful deprescribing process, particularly one that also reduces sex disparities in PD outcomes. It is critical to understand patients' expectations from the physician–patient relationship regarding managing their medication load. For example, a given patient might prefer to tolerate the adverse effects of a medication rather than deal with withdrawal symptoms when discontinuing it, even if the medication is no longer beneficial, or physicians might continue prescribing a medication out of convenience. In such cases, neither party may be willing to change their behavior. However, our study showed that patients are open to and might even want to participate in the conversation about deprescribing initiated by their physician. Furthermore, our dataset did not include information on the respondents' stages or duration of PD, which could influence their perception of medication burden and

attitudes towards deprescribing as the disease progresses. Future studies will examine the association between patient willingness to deprescribe and validated measures of disease severity. We may find that deprescribing is more or less welcome at advanced stages. Finding that dissatisfaction in treatment is highly prevalent even at an early stage, among functional patients with well-treated disease may provide insight into the disease itself and have implications for intervention strategies. Lastly, our dataset did not have information on specific medications, including any anticholinergics that respondents might have been taking, which prevented us from distinguishing between medications with central vs. peripheral anticholinergic effects and from highlighting potentially inappropriate anticholinergics with no clear indications or benefits in this study sample. Therefore, while we support optimizing overall therapy through appropriate prescribing practices to minimize unnecessary polypharmacy in individuals with PD without causing undue fear of medications, we were unable to provide specific recommendations on which medications to target for deprescribing in this patient population. Future studies on deprescribing interventions should focus on specific PIMs, especially those that cross the blood–brain barrier in the case of anticholinergics.

Conclusions

Our findings suggest that persons living with PD are willing to discontinue their medications, especially following physicians' suggestions and guidance. More importantly, they want to avoid cognitive impairment or lower future dementia risk when prescribed medications for nonmotor symptoms of PD. Deprescribing interventions in PD may need to be tailored to sex differences in treatment views and preferences to prevent the development of interventions that do not improve or may worsen known sex disparities in PD care.

Abbreviations

PIMs	Potentially inappropriate medications
PD	Parkinson disease
rPATD	Revised Patients' Attitudes to Deprescribing
aOR	Adjusted odds ratio

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s12883-024-03830-w.

Supplementary Material 1: Supplementary Figure 1. Potential adverse effects participants would like to avoid the most if prescribed a new medication for urinary problems (*n*=4460*). Supplementary Figure 2. Potential adverse effects participants would like to avoid the most if prescribed a new medication for mood (*n*=4413*). Supplementary Figure 3. Potential adverse effects participants would like to avoid the most if prescribed a new medication for hallucinations (*n*=4386*).

Supplementary Material 2.

Supplementary Material 3.

Supplementary Material 4.

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Authors' contributions

A.G.H. and A.W.W. designed and organized the research project. All authors executed the research project. T.P.P.N. designed the statistical analysis. D.T. executed the statistical analysis. T.P.P.N. and A.W.W. reviewed and critiqued the analysis, and prepared the first draft of the manuscript. All authors reviewed and critiqued the manuscript and approved the final draft of the manuscript.

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Availability of data and materials

Data used to prepare this article were obtained from the Fox Insight database (https://foxinsight-info.michaeljfox.org/insight/explore/insight.jsp) on March 20, 2023. The datasets generated and analyzed during the current study are not publicly available. For up-to-date information on the Fox Insight Study, please visithttps://foxinsight-info.michaeljfox.org/insight/explore/insight.jsp.

Declarations

Ethics approval and consent to participate

The Institutional Review Board (IRB) of the University of Pennsylvania approved this survey (protocol #833498). The New England IRB approved the Fox Insight study. All Fox Insight participants gave informed consent, and if unable, a legal guardian gave consent by proxy at enrollment.

Consent for publication

Not applicable.

Competing interests

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References

1. By the American Geriatrics Society Beers Criteria Update Expert Panel. American Geriatrics Society 2023 updated AGS Beers Criteria(R) for potentially inappropriate medication use in older adults. J Am Geriatr Soc. 2023;71 7:2052–81. https://doi.org/10.1111/jgs.18372.
2. Abraham DS, Pham Nguyen TP, Hennessy S, Weintraub D, Gray SL, Xie D, et al. Frequency of and risk factors for potentially inappropriate medication use in Parkinson's disease. Age Ageing. 2020;49(5):786–92. https://doi.org/10.1093/ageing/afaa033.

3. Sonnerstam E, Harlin F, Gustafsson M. Potentially inappropriate medications among elderly people with neurocognitive disorders - A nationwide register-based study using 3 different explicit criteria. Res Social Adm Pharm. 2023;19(5):758–63. https://doi.org/10.1016/j.sapharm.2023.01.010.
4. Mantri S, Fullard M, Gray SL, Weintraub D, Hubbard RA, Hennessy S, et al. Patterns of Dementia Treatment and Frank Prescribing Errors in Older Adults With Parkinson Disease. JAMA Neurol. 2019;76(1):41–9. https://doi.org/10.1001/jamaneurol.2018.2820.
5. Aarsland D, Batzu L, Halliday GM, Geurtsen GJ, Ballard C, Ray Chaudhuri K, et al. Parkinson disease-associated cognitive impairment. Nat Rev Dis Primers. 2021;7 1:47; https://doi.org/10.1038/s41572-021-00280-3.
6. Pondal M, Del Ser T, Bermejo F. Anticholinergic therapy and dementia in patients with Parkinson's disease. J Neurol. 1996;243(7):543–6. https://doi.org/10.1007/BF00886877.
7. Ehrt U, Broich K, Larsen JP, Ballard C, Aarsland D. Use of drugs with anticholinergic effect and impact on cognition in Parkinson's disease: a cohort study. J Neurol Neurosurg Psychiatry. 2010;81(2):160–5. https://doi.org/10.1136/jnnp.2009.186239.
8. Hong CT, Chan L, Wu D, Chen WT, Chien LN. Antiparkinsonism anticholinergics increase dementia risk in patients with Parkinson's disease. Parkinsonism Relat Disord. 2019;65:224–9. https://doi.org/10.1016/j.parkreldis.2019.06.022.
9. Sheu JJ, Tsai MT, Erickson SR, Wu CH. Association between Anticholinergic Medication Use and Risk of Dementia among Patients with Parkinson's Disease. Pharmacotherapy. 2019;39(8):798–808. https://doi.org/10.1002/phar.2305.
10. Reeve E, Thompson W, Farrell B. Deprescribing: A narrative review of the evidence and practical recommendations for recognizing opportunities and taking action. Eur J Intern Med. 2017;38:3–11. https://doi.org/10.1016/j.ejim.2016.12.021.
11. Ailabouni NJ, Rebecca Weir K, Reeve E, Turner JT, Wilson Norton J, Gray SL. Barriers and enablers of older adults initiating a deprescribing conversation. Patient Educ Couns. 2022;105(3):615–24. https://doi.org/10.1016/j.pec.2021.06.021.
12. Smolensky L, Amondikar N, Crawford K, Neu S, Kopil CM, Daeschler M, et al. Fox Insight collects online, longitudinal patient-reported outcomes and genetic data on Parkinson's disease. Sci Data. 2020;7 1:67; https://doi.org/10.1038/s41597-020-0401-2.
13. Reeve E, Wiese MD, Hendrix I, Roberts MS, Shakib S. People's attitudes, beliefs, and experiences regarding polypharmacy and willingness to Deprescribe. J Am Geriatr Soc. 2013;61(9):1508–14. https://doi.org/10.1111/jgs.12418.
14. Reeve E, Wolff JL, Skehan M, Bayliss EA, Hilmer SN, Boyd CM. Assessment of Attitudes Toward Deprescribing in Older Medicare Beneficiaries in the United States. JAMA Intern Med. 2018;178(12):1673–80. https://doi.org/10.1001/jamainternmed.2018.4720.
15. Buzancic I, Dragovic P, Pejakovic TI, Markulin L, Ortner-Hadziabdic M. Exploring Patients' Attitudes Toward Deprescribing and Their Perception of Pharmacist Involvement in a European Country: A Cross-Sectional Study. Patient Prefer Adherence. 2021;15:2197–208. https://doi.org/10.2147/PPA.S323846.
16. U.S. Census Bureau. Census Bureau Releases New Educational Attainment Data. https://www.census.gov/newsroom/press-releases/2023/educational-attainment-data.html (2023). Accessed January 4 2024.
17. Ng WL, Tan MZW, Koh EYL, Tan NC. Deprescribing: What are the views and factors influencing this concept among patients with chronic diseases in a developed Asian community? Proceedings of Singapore Healthcare. 2017;26(3):172–9. https://doi.org/10.1177/2010105817699633.
18. Kua CH, Reeve E, Tan DSY, Koh T, Soong JL, Sim MJL, et al. Patients' and Caregivers' Attitudes Toward Deprescribing in Singapore. J Gerontol A Biol Sci Med Sci. 2021;76 6:1074; https://doi.org/10.1093/gerona/glaa062.
19. Crutzen S, Abou J, Smits SE, Baas G, Hugtenburg JG, Heringa M, et al. Older people's attitudes towards deprescribing cardiometabolic medication. BMC Geriatr. 2021;21 1:366; https://doi.org/10.1186/s12877-021-02249-z.
20. Growdon ME, Espejo E, Jing B, Boscardin WJ, Zullo AR, Yaffe K, et al. Attitudes toward deprescribing among older adults with dementia in the United States. J Am Geriatr Soc. 2022;70(6):1764–73. https://doi.org/10.1111/jgs.17730.
21. Edelman M, Jellema P, Hak E, Denig P, Blanker MH. Patients' Attitudes Towards Deprescribing Alpha-Blockers and Their Willingness to Participate in a Discontinuation Trial. Drugs Aging. 2019;36(12):1133–9. https://doi.org/10.1007/s40266-019-00712-6.
22. Tegegn HG, Tefera YG, Erku DA, Haile KT, Abebe TB, Chekol F, et al. Older patients' perception of deprescribing in resource-limited settings: a cross-sectional study in an Ethiopia university hospital. BMJ Open. 2018;84:e020590; https://doi.org/10.1136/bmjopen-2017-020590.
23. Pereira A, Ribeiro O, Verissimo M. Predictors of older patients' willingness to have medications deprescribed: A cross-sectional study. Basic Clin Pharmacol Toxicol. 2023;133(6):703–17. https://doi.org/10.1111/bcpt.13874.
24. Dahodwala N, Shah K, He Y, Wu SS, Schmidt P, Cubillos F, et al. Sex disparities in access to caregiving in Parkinson disease. Neurology. 2018;90(1):e48–54. https://doi.org/10.1212/WNL.0000000000004764.
25. Patel R, Kompoliti K. Sex and Gender Differences in Parkinson's Disease. Neurol Clin. 2023;41(2):371–9. https://doi.org/10.1016/j.ncl.2022.12.001.
26. Barrett MJ, Sargent L, Nawaz H, Weintraub D, Price ET, Willis AW. Antimuscarinic Anticholinergic Medications in Parkinson Disease: To Prescribe or Deprescribe? Mov Disord Clin Pract. 2021;8(8):1181–8. https://doi.org/10.1002/mdc3.13347.
27. Carriere I, Fourrier-Reglat A, Dartigues JF, Rouaud O, Pasquier F, Ritchie K, et al. Drugs with anticholinergic properties, cognitive decline, and dementia in an elderly general population: the 3-city study. Arch Intern Med. 2009;169(14):1317–24. https://doi.org/10.1001/archinternmed.2009.229.
28. Richardson K, Fox C, Maidment I, Steel N, Loke YK, Arthur A, et al. Anticholinergic drugs and risk of dementia: case-control study. BMJ. 2018;361:k1315. https://doi.org/10.1136/bmj.k1315.
29. Coupland CAC, Hill T, Dening T, Morriss R, Moore M, Hippisley-Cox J. Anticholinergic Drug Exposure and the Risk of Dementia: A Nested Case-Control Study. JAMA Intern Med. 2019;179(8):1084–93. https://doi.org/10.1001/jamainternmed.2019.0677.
30. Chuang YF, Elango P, Gonzalez CE, Thambisetty M. Midlife anticholinergic drug use, risk of Alzheimer's disease, and brain atrophy in community-dwelling older adults. Alzheimers Dement (N Y). 2017;3(3):471–9. https://doi.org/10.1016/j.trci.2017.06.004.

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