

Cannabis use in Parkinson's disease—A nationwide online survey study

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Abstract

Objectives: The aim of this study was to investigate the frequency of use, attitudes toward, and experiences with cannabis and cannabis-related products among people with Parkinson's disease (PwP) living in Norway.

Methods: Between February and August 2021, PwP and their caregivers were invited to participate in an anonymous online survey study on cannabis use. $N = 530$ PwP completed the 24-item survey collecting data on the participants' history of cannabis use, perceived benefits and adverse effects of cannabis use, and expectations toward health care professionals. $N = 108$ caregivers completed a brief survey detailing their experience with cannabis use.

Results: A total of 59 (11.3%) of PwP reported previous or current use of cannabis, compared to 7 (6.6%) of caregivers. Cannabis use was associated with increased disease duration, but not age or gender. Improvement in motor function (69.5%), sleep (52.5%), and pain (37.3%) was the most frequently perceived benefits of cannabis use, with benefits more frequently reported by current than previous users. While half (50.8%) of cannabis users had sought advice from a health care professional regarding cannabis use, only 55 (19.9%) of non-users with an interest in cannabis use had discussed the topic with health care professionals. Principal barriers for discussing cannabis use with health care professionals are discussed.

Conclusions: One in 20 PwP reports cannabis use, and non-users report widespread interest in cannabis. The use of cannabis is often not reported and unknown for health care professionals, arguing for a vigilant approach to non-prescribed cannabis use in clinical follow-up of PwP.

KEYWORDS

cannabidiol, cannabis, delta-9-tetrahydrocannabinol, Parkinson's disease

1 | INTRODUCTION

Continued efforts to identify novel and effective management strategies for Parkinson's disease (PD) are of crucial importance for patients and their caregivers. Recently, the potential for clinical use

of medical cannabis in PD has been the subject of increased focus among patients, researchers, and clinicians.¹⁻⁴ Although there is a lack of clear evidence supporting the efficacy of medical cannabis in the management of PD,⁴ some patients and researchers argue that medical cannabis, or some of the cannabinoids in the cannabis plant,

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may alleviate motor and non-motor symptoms in PD.⁵ Following widespread publicity about the potential benefits of cannabinoids for motor and non-motor symptoms of PD, questions regarding the efficacy and availability of cannabinoid products have increased in clinical practice, and off-label use has been reported to be between 4 and 25% in the United States, Germany, and the Czech Republic.^{2,6-9} The variability in estimates may be caused by several factors, such as differences in methodology used in these studies, and cultural differences in the perception of cannabis use and the legality of use, and annual use of cannabis and cannabis-related products across nations.¹⁰

Given that cannabinoid products are costly and unregulated in most European countries, there is an urgent need for thorough scientific inquiry into the potential clinical utility of cannabinoids for people with PD (PwP).¹¹ Against this background, we conducted an anonymous online survey study to investigate the frequency of use, attitudes toward, and experiences with cannabis and cannabis-related products among PwP living in Norway.

2 | MATERIALS AND METHODS

2.1 | Study design and participants

The Can-PD survey is an anonymous online survey of cannabis use patterns among PwP and their caregivers. PwP and their caregivers were invited to participate between February and August 2021. The recruitment strategy was broad and included e-mails, Facebook posts, and podcasts/webinars to members of the Norwegian Parkinson's Disease Association (N-PA), and an online invitation on the webpages of the Norwegian Centre for Movement Disorders. The N-PA has approximately 3500 members with PD and 1000 members who are caregivers. A total of $N = 530$ participants with PD and $N = 108$ caregivers agreed to participate in this study. Ten participants with PD and two caregivers did not meet the inclusion criteria and were subsequently excluded from further analysis. Signed written informed consent was obtained from all participants. Participants were ensured that no legal consequences will result from participation in the study. This guarantee was stated in all recruitment materials used and repeated twice in the informed consent. The study was approved by the Regional Committee for Medical and Health Research Ethics, Western Norway (# 129890).

The inclusion criteria included signed written informed consent; people with a self-reported diagnosis of Parkinson's disease, or people caring for people with Parkinson's disease. Exclusion criteria were participants with self-reported conditions that may limit their capacity to make decisions or to understand that the survey is voluntary (i.e., dementia and/or psychosis).

Data gathering was performed on the TSD (Tjeneste for Sensitive Data) facilities, owned by the University of Oslo, operated and developed by the TSD service group at the University of Oslo, IT Department (tsd-drift@usit.uio.no). The TSD platform provides a secure environment that meets legal requirements regarding privacy

and protection of sensitive data. Furthermore, a PGP-encrypted version of the UiO web-questionnaire (Nettskjema), interfaced with the governmental ID-portal for login, was used to administer the survey, ensuring both secure data harvesting and robust identification of the respondents. Survey data were automatically de-identified by the TSD system before any analyses were performed. The study was approved by the Regional Committee for Medical and Health Research Ethics, Western Norway (# 129890), and the Norwegian Centre for Research Data.

2.2 | Survey content

The Can-PD survey is a 24-item survey of cannabis use patterns among PwP and their caregivers. This survey is a modified and extended version of a survey provided by the UK-based user organization, Parkinson's UK. The survey was adapted to suit a Norwegian setting, and two users from the N-PA provided feedback during the development of the items.

The survey consists of items investigating disease duration, demographic variables, and history of cannabis use. PwP currently using cannabis or cannabis-related products (CU), or PwP who previously used cannabis or cannabis-related products (PU), completed 17 or 16 items, respectively. These items further investigate the cannabis use pattern with regard to type of cannabis product, dosage and frequency of use, costs, benefits of use, adverse reactions, and contact with health care professionals. PwP who are considering starting to use cannabis or cannabis-related products completed 12 items investigating what type of cannabis product, plans for acquiring the product, expected benefits or adverse effects of use, and contact with health care professionals regarding cannabis or cannabis-related products. Lastly, all participants with PD complete seven items on their attitudes toward clinical trials and participation in such studies. For participants who are caregivers of patients with PD, a three- to seven-item questionnaire, including items measuring demographics, details on pattern of use, and plans for acquiring the product, is presented.

Most items on the survey were scored using categorical variables. Free-text options were available on most categorical survey items. One set of items pertaining to the self-reported effects of cannabis products on specific symptoms was scored on a Likert scale ranging from 0 to 4. Here, scores were labeled as 0 = "not applicable," 1 = "no effects," 2 = "small effect," 3 = "moderate effect," and 4 = "large effect." Symptoms related to five symptoms clusters were included: (a) motor symptoms: dystonia, slowness, stiffness, tremor, dyskinesia, posture, balance issues, and falls; (b) neuropsychiatric symptoms: pain, anxiety, apathy, depression, impulse control disorders, and delusions; (c) cognitive symptoms: memory difficulties and difficulties with attention; (d) sleep difficulties: intense or lifelike dreams, sleep difficulties, and difficulties staying awake during the day; (e) gastrointestinal and other symptoms: incontinence, constipation, difficulties eating or drinking, dizziness, drooling, and nausea.

2.3 | Statistical methods

All continuous data were evaluated using histograms, Q-Q-plots, and Kolmogorov–Smirnov tests. Comparisons between groups were performed using Student's *T*-tests, Chi-square tests, Fisher's exact test, and one-way ANOVA. Group differences on nonparametric data (age and disease duration) were estimated using Kruskal–Wallis *H* test.

3 | RESULTS

3.1 | Participant characteristics and reported cannabis use in PwP and caregivers

Participant characteristics are summarized in Table 1. Participants with PD were significantly older than caregivers (65.5 ± 8.6 vs. 58.1 ± 15.9 , $p < .001$) and more likely to be male ($\chi^2 = 38.6$, $p < .001$). There was a significant difference between the two groups in the frequency of current cannabis use ($p = .034$), but no difference in previous cannabis use ($p = .609$).

Among PwP, a total of 11.3% ($N = 59$) PwP reported previous or current use of a cannabis product, while 88.7% ($N = 461$) reported no history of cannabis use. 4% ($N = 21$) of participants reported CU, and 7.3% ($N = 38$) reported PU. These groups did not differ in age or gender, but there was a significant difference in median disease duration between the groups ($H(2) = 15.7$, $p < .001$), with both current users ($Mdn = 6.0$) and previous users of cannabis ($Mdn = 7.5$) reporting longer disease duration compared to those who have never used ($Mdn = 5.0$). Group characteristics are summarized in Table 2.

3.2 | Use characteristics of current and previous cannabis users with PD

The patterns of cannabis use are summarized in Table 3 and supplemental materials E-1. Both the CU and PU groups reported CBD oil (CU 66.7% and PU 78.9%) as the most frequently used cannabis type, followed by hashish or street cannabis (CU 23.8% and PU 18.4%), and Sativex (CU 14.3% and PU 2.6%). The frequency of use was at least daily for 66.7% of CU and 71.1% of PU, with the average weekly cost for both groups ranging between 0 and 3000 NOK (\approx €300). Both groups reported symptom management (CU 95.2%

and PU 76.3%), relaxation (CU 33.3% and PU 13.2%), and neuro-protection/stop progression of PD (CU 9.5% and PU 18.4%) as the primary reasons for cannabis use. Negative effects of cannabis use were rarely reported (CU 4.8% and PU 5.6%), and interaction effects between cannabis and prescribed medication for PD were reported by only two participants (CU 4.8% and PU 2.3%).

In the PU group, reasons for terminating use were: reporting no significant effect of usage (44.7%), worries about breaking the law (26.3%), the cost of cannabis (23.7%), worries about side effects (13.2%), and other (26.3%).

Benefits of use were frequently reported among the CU group, with reported benefits seen in all symptom clusters. The most common benefits reported were improvement in motor symptoms (95.2%), followed by improvements in sleep (76.2%), and pain (52.4%). Although benefits were reported less frequently in the PU group, they followed the same pattern, with improvements most frequently reported for motor symptoms (55.3%), sleep disturbances (39.5%), and pain (28.9%). For both groups, the top three single symptoms most frequently reported to improve with the use of cannabis were stiffness, tremor, and sleep disturbances (see Table S1 for details).

3.3 | Attitudes toward health care advice for cannabis use among users

Of the 59 PwP who had experience with cannabis use, $N = 30$ (50.8%) had sought advice from health care professionals regarding their cannabis use, while $N = 29$ (49.2%) had not. The barriers reported for seeking advice from health care professionals included: low expectations toward the health care professionals' interest or knowledge about this topic ($N = 6$), fear of negative consequences ($N = 5$), not wanting to disclose non-prescribed treatments to health care professionals ($N = 8$), and other reasons ($N = 10$).

3.4 | Attitudes toward cannabis in non-users with PD

Among the $N = 461$ PwP with no cannabis use experience, 276 (59.8%) reported an interest in treatment with cannabis. The reported reasons for their interest in cannabis included improvement of PD symptoms ($N = 240$), slowing disease progression ($N = 176$), relaxation ($N = 69$), or other reasons ($n = 11$).

Characteristics	PwP ($N = 520$)	Caregiver ($N = 106$)	<i>p</i> -value
Age, years, median (IQR)	67 (60–71)	63 (49–70)	.001
Male, <i>n</i> (%)	336 (61.3)	34 (52.6)	.001
PD duration, years, median (IQR)	5 (3–9)	–	–
Current cannabis use, <i>n</i> (%)	21 (4.0)	0 (0)	.035
Previous cannabis use, <i>n</i> (%)	38 (7.3)	7 (6.6)	.798

TABLE 1 Demographic and clinical characteristics of PwP and caregivers.

Note: Abbreviations: IQR, interquartile range; PD, Parkinson's disease; PwP, people with Parkinson's disease.

TABLE 2 Demographic and clinical characteristics among PwP, stratified by cannabis use history.

Characteristics	Current use (N = 21)	Previous use (N = 38)	Never use (N = 461)	p-value
Age, years, median (IQR)	68 (63–73.5)	65 (58–69)	67 (60–71.5)	.276 ^a
Male, n (%)	12 (57.1)	22 (57.9)	184 (66.6)	.609
PD duration, years, median (IQR)	6 (5–11)	7.5 (5–11)	5 (2–8)	.001 ^a

Note: Abbreviation: PD, Parkinson's disease.

^aResults of Kruskal–Wallis H test.

TABLE 3 Cannabis use characteristics among current and previous users of cannabis.

Characteristics	PD—all cannabis users (N = 59)	PD—current use (N = 21)	PD—previous use (N = 38)	Caregiver—current use (N = 7)
Type of cannabis product ^a				
CBD-oil	44 (74.6)	14 (66.7)	30 (78.9)	2 (28.6)
Sativex	4 (6.8)	3 (14.3)	1 (2.6)	0 (0)
Hashish/street cannabis	12 (20.3)	5 (23.8)	7 (18.4)	6 (85.7)
THC oil with inhaler	0 (0)	0 (0)	0 (0)	0 (0)
Cannabis in food	2 (3.4)	2 (9.5)	0 (0)	4 (57.1)
In tea	2 (3.4)	2 (9.5)	0 (0)	0 (0)
Other	5 (8.5)	0 (0)	5 (13.2)	0 (0)
Reasons for use ^a				
Relaxation	12 (20.3)	7 (33.3)	5 (13.2)	4 (57.1)
Stop development of PD	9 (15.3)	2 (9.5)	7 (18.4)	-
Symptom management	49 (83.0)	20 (95.2)	29 (76.3)	4 (57.1)
Other	12 (20.3)	2 (9.5)	10 (26.3)	5 (71.4)
Reported benefits for symptoms clusters ^b				
Motor symptoms	41 (69.5)	20 (95.2)	21 (55.3)	-
Pain	22 (37.3)	11 (52.4)	11 (28.9)	-
Neuropsychiatric symptoms	16 (27.1)	8 (38.1)	8 (21.1)	-
Cognition	10 (16.7)	6 (28.6)	4 (10.5)	-
Sleep disturbances	31 (52.5)	16 (76.2)	15 (39.5)	-
Gastrointestinal & other	15 (25.4)	9 (42.9)	6 (15.8)	-
At least daily cannabis use	41 (69.5)	14 (66.7)	27 (71.1)	2 (28.6)
Average monthly cost in NOK, mean (SD)	701 (743)	538 (474) ^c	788 (853)	1200 (1264)

Note: All data are n (%), unless otherwise specified.

Abbreviation: PD, Parkinson's disease.

^aMultiple choices were available. Possible choices were predefined in the survey, but a free-text option was available.

^bNumber of participants with a score above "1 = no effect", indicating a positive effect of cannabis use on one or more symptom in this symptom cluster.

^cN = 9 participants provided information of the average monthly cost of their cannabis use.

Among the N=276 with an interest in cannabis treatment, N = 55 (19.9%) had sought advice from health care professionals. While several barriers were reported by participants who had not sought advice, the most common was a belief that the health care professional would recommend against cannabis use (N = 94, 42.5%). Additional barriers to seeking health care advice included low expectations toward the health care professionals' interest or knowledge about this topic (N = 96, 34.8%), fear of negative consequences (N = 156, 22.5%), not wanting to disclose non-prescribed treatments to health care professionals (N = 21, 9.5%), and other reasons (N = 57, 25.8%).

4 | DISCUSSION

In this cross-sectional online survey study, 11.3% of PwP in Norway reported experience with cannabis compared to 6.6% of caregivers. This difference was driven by differences in current rather than previous use. Current cannabis use was motivated by a desire for better symptom management.

The findings of this study expand our current knowledge about cannabis use among PwP in several ways. First, past or current cannabis use was seen in 11% of PwP who responded to the survey. This

frequency estimate is higher than that observed in the United States (4%) and Germany (8%), significantly lower than data from the Czech Republic (25%), but in line with frequency estimates from the United Kingdom (13%).^{2,6,8,9} The rate of cannabis use is most likely dependent upon several factors, such as the legality of cannabis, cultural norms surrounding cannabis use, and the cost and availability of cannabis. In the Norwegian setting, cannabis use, import, and storage are illegal, and cannabis use is mainly seen among adolescents and young adults in the general population.¹² Indeed, in Norway cannabis use is rare following adolescence and has been associated with increasing social marginalization with increasing age.^{13,14} The high rate of cannabis use in PwP in the Norwegian setting is, therefore, noteworthy and argues that the discourse on cannabis among PwP may also result in increased use. Still, these data should be interpreted with caution due to the lack of survey data from this age strata in the general population of Norway. Also, comparisons between countries are difficult as all published survey studies have utilized convenience sampling, and cultural differences between countries may impact the results.

Second, we identified an association between cannabis use and longer duration of PD. This is of interest as previous studies conducted in Germany and the Czech Republic reported such use to be most common among younger PwP and those with shorter disease duration.^{8,9} Our findings modify this view, suggesting that non-prescribed cannabis use is not limited to the initial phase of PD, but also seen in patients with longer disease duration, where the clinical and functional problems usually are more complex.

Third, in the current study, PwP who are currently using cannabis or cannabis-related products report several favorable benefits from their use, including benefits on motor, sleep, and pain-related symptoms.^{5,6,8,9} These findings are in line with results from other survey-based studies,^{5,6,8,9} but contrasts results of controlled studies, which challenge the notion that cannabis or cannabis-related products are viable for the treatment of motor symptoms in PD.¹⁵ Potential explanations for these inconsistencies include methodological differences between studies in cannabis formula or cannabis dosage used, and length of follow-up. Worth noting, randomized controlled trials and observational studies in this field generally use different outcome measures, possibly introducing a bias to placebo effects in observational studies.¹⁵ In order to clarify this discrepancy, future studies should include both objective and subjective measures of motor symptoms.

Addressing cannabis use in clinical practice can be difficult, due to both a lack of sound empirical data on potential treatment effects and a lack of consensus in the field.¹¹ Following the widespread interest in cannabis among PwP (>60% based on this study and previous reports⁹), our results show that many patients perceive that there are barriers that deter them from contacting health care professionals. While many expect to be advised against cannabis use by health care professionals, several PwP fear negative consequences and have low expectations toward health care professionals on this topic. These findings are important for clinical practice, as these barriers may hinder the identification of patients using these products. Also, the frequent interest in cannabis among PwP indicates a need for the development of novel effective treatment strategies for PwP.

This study has several strengths and limitations. Major limitations include the use of convenience sampling gathered mainly using online tools (e-mails, web-posts, webinars, and podcasts) and methodological issues inherent to survey studies, including recall bias and social desirability. In addition, there is a possibility of selection bias due to, for example, anonymity concerns or varying interest in the topic of cannabis among PwP. Still, the mean age and gender distribution of our cohort are very similar to those observed in the general Norwegian PwP population,¹⁶ arguing against major skewness of the sample studied here. Main strengths of this study include the comprehensiveness of the survey and the high number of participants ($N = 520$), with a coverage of about 15% of PwP members in the N-PA ($N \approx 3500$) and 7% of the estimated total PD population in Norway ($N = 7000$). Additional strengths of this study are the involvement of user representatives in the survey design and the collaboration with the national patient organization in the recruitment of participants.

5 | CONCLUSION

One in 20 PwP reports cannabis use, with a high percentage of PwP reporting benefits of cannabis use. For both PwP using cannabis and PwP with an interest in cannabis, barriers may deter them from contacting health care professionals for advice regarding the use of cannabis. In order to further help clinicians and user organizations provide evidence-based health information to PwP using or considering using cannabis or cannabis-related products, longitudinal data are needed. Clinical studies using standardized cannabis dosages are also warranted given the high frequency of benefits of use seen in current users.

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CONFLICT OF INTEREST

All authors have no conflict of interest.

AUTHOR CONTRIBUTIONS

AHE contributed to study concept and design, analysis and interpretation of data, and writing of the first draft. JMG and GA contributed to study concept and design, analysis and interpretation of data, and critical revision of the manuscript for important intellectual content.

ETHICS APPROVAL

The study was approved by the Regional Committee for Medical and Health Research Ethics, Western Norway.

PATIENT CONSENT

Signed written informed consent was obtained from all participants.

PEER REVIEW

The peer review history for this article is available at <https://publons.com/publon/10.1111/ane.13602>.

DATA AVAILABILITY

The data that support the findings of this study are available in anonymized form from the corresponding author upon reasonable request. Please contact the corresponding author.

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SUPPORTING INFORMATION

Additional supporting information may be found in the online version of the article at the publisher's website.

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