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Phenomenology and gender characteristics of hobbyism and punding in Parkinson's disease: A self-report study

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Running title:

Hobbyism and punding in PD

Abstract
Objectives: Dopamine replacement therapy administered to alleviate motor symptoms of Parkinson's disease (PD) has been linked to a range of impulsive and compulsive behaviors (ICBs). The objective of the current study is to describe the phenomenology and delineate gender characteristics of hobbyism and punding in PD based on self-report.
Materials and methods: We applied two self-report questionnaires. A clinical and demographic questionnaire assessing motor symptomatology and the short-version of the Questionnaire for impulsive-compulsive behaviors in PD assessing symptoms of current and past ICBs in PD.
Results: Results suggest that hobbyism and punding are very common among Danish patients with PD with 27.5% of patients reporting symptoms hereof in the current sample. Furthermore, findings indicate that male and female patients engage differently in hobbyism and punding showing different preferences for specific compulsive activities. In addition, hobbyism and punding appear to be very time consuming with up to 10.6% of patients spending more than five hours each day on these behaviors. We found no significant gender differences in time consumption nor in the subjective experience of being pre-occupied with and feeling loss of control over the behavior. However, unlike men only very few female patients (12.1%) addressed a healthcare professional about ICB symptoms overall, and none when considering hobbyism and punding alone. Finally, findings suggest that age at PD onset and advanced motor symptomatology are significantly associated with hobbyism and punding, respectively, in both male and female patients with PD, whereas non-cardinal motor symptoms, only predict ICBs in male patients.
Conclusions: Findings may have important clinical implications in early identification of ICBs in male and female patients with PD by emphasizing the need for healthcare professionals to explicitly ask patients about behavioral alterations and taking motor symptomatology into account when screening for ICBs in PD.

Keywords: Gender, Hobbyism, Impulse control disorders, Motor symptomatology, Parkinson's disease, Punding.

Introduction

Parkinson's disease (PD) is a progressive neurodegenerative disorder characterized by continuous dopamine depletion in the midbrain resulting in cardinal motor symptoms of bradykinesia, rigidity, tremor, and postural instability [1]. Additional non-cardinal motor symptoms include e.g. freezing of gait, swallowing problems, dyskinesia, and pain and numbness [1]. Dopamine replacement therapy such as levodopa and dopamine agonists administered to relieve motor symptoms, are sometimes accompanied by various adverse cognitive effects including impulse control disorders [2, 1, 3-6].

Impulse control disorders in PD have been shown to affect up to 16% of patients [7, 8] with compulsive sexual behavior, compulsive buying, pathological gambling, and binge eating being the

most prevalent subtypes in PD. In addition, various related compulsive behaviors including hobbyism (i.e. intense engagement in specific activities such as excessive computer use, writing, repairing or dismantling objects), punding (i.e. repetitive stereotyped behavior such as cleaning, tidying, and arranging objects), and compulsive use of dopaminergic medication have also been identified in PD [7, 9, 8]. We have previously demonstrated that among Danish patients with PD 35.9% experience symptoms of such impulsive and compulsive behaviors (ICBs) sometime during the course of their disease with hobbyism and punding being the most commonly reported subtypes [9]. However, the clinical nature of hobbyism and punding in PD remains understudied.

Impulse control disorders as well as mere symptoms of ICBs may have a potentially negative impact on patients' quality of life, finances, and social functioning and induce an increased caregiver burden [10]. Thus it is of utmost clinical importance to quickly identify patients at risk for developing ICBs. Currently several risk factors have been associated with ICBs in PD such as young age, early PD onset, male gender, personal or family history of addictive behaviors, genetic factors, depressive symptomatology, distinct personality profiles of increased impulsivity and novelty seeking, increased levels of neuroticism, and decreased levels agreeableness and conscientiousness, and a high dose of dopamine replacement therapy, dopamine agonists in particular [9, 7, 11-15, 5, 16-23]. Erga and colleagues [22] recently demonstrated that while levodopa alone does not increase the odds of ICBs markedly, dopamine agonists, especially when administered as monotherapy, increase the risk of ICBs more than 7 times. In addition, the manifestation of specific ICB subtypes may be influenced by gender: for instance compulsive sexual behavior appear more prevalent among male patients while compulsive buying and binge eating more commonly affect female patients [21]. However, only little attention has been paid to if and how gender affects the extent to which patients engage in ICBs and whether or not patients subjectively experience ICB symptoms as problematic and interfering with their daily life. At this time, there is a growing interest within the field of PD research in assessing and understanding the impact of gender differences in the course and management of PD. Recent studies indicate that despite the fact that PD is slightly more prevalent among men than women, female patients tend to display more severe motor symptomatology and a more rapid progression of PD but also more disabling non-motor symptoms of e.g. depression, anxiety, and sleep-disturbances than male patients [24]. On the other hand, male patients more often experience apathy and sexual dysfunctions [24]. It is likely, that such gender differences also impact the phenomena of ICBs, including hobbyism and punding, in PD.

Similarly, a paucity of studies addressing issues of early identification of subtypes of ICBs in PD and management thereof seems to exist. Furthermore, it appears that despite the negative consequences of ICBs, patients seldom present symptoms to healthcare professionals, which may be related to patients underestimating or denying the presence and severity of ICBs [10, 25, 26] e.g. due to lack of insight [27] or unwillingness to reveal behavioral symptoms [28].

The aim of the current study is to explore the phenomenology and gender characteristics of hobbyism and punding in PD based on patients' subjective experience, which could potentially provide guidance to clinicians towards timely detection of these behavioral complications to the treatment of PD. Thus, we address the following research questions: i) do male and female patients with PD engage differently in hobbyism and punding?; ii) do male and female patients with PD disclose issues of hobbyism and punding to their doctor or neurologist equally often?; and finally iii) do different constellations of motor symptomatology predict hobbyism and punding differently in male and female patients with PD?

Materials and methods

Participants

A community dwelling sample of 914 patients with a diagnosis of PD was invited to partake in the present study. The sample was identified through the Danish National Patient Registry and encompassed all patients diagnosed by a neurologist with idiopathic PD residing in the middle and northern part of Jutland, Denmark. The Danish National Patient Registry is a social security number based register of all somatic and psychiatric diagnoses given to any individual citizen in the entire Danish population by a licensed medical doctor, including neurologists and psychiatrists. Exclusion criteria were a) registered diagnosis of dementia (ascertained by a neurologist) and suspected dementia (presented by other healthcare professionals), b) registered diagnosis of other neurological or neurodegenerative disorders than PD (including atypical PD and Parkinson plus), c) previous history of strokes or brain tumors, d) registered diagnosis of personality disorders. A total of 753 patients (57.5% men) responded, hereof 504 patients returned the questionnaires while 249 patients replied that they did not wish to participate. Fourteen of the 504 patients were excluded due to incomplete questionnaire data, leading to a final sample of 490 participants. For a detailed description of the sample and the procedure please see Callesen et al. 2014 [9].

All participants gave written informed consent prior to participating in the study, which was

approved by the local ethical committee and the National Danish Data Protection Agency and conducted according to the Helsinki declaration.

Measures

For the purpose of the current study we included two measures: 1) A demographic and clinical questionnaire consisting of 24 items providing details on age at PD onset, disease duration, motor symptomatology (10 yes/no questions about tremor, ON/OFF periods, postural instability, bradykinesia, rigidity, dyskinesia, freezing, problems swallowing, and muscle pain or numbness), PD medication, physical and mental health besides PD, smoking habits, drug abuse, and family history of PD and drug abuse. This measure was not used to diagnose PD as all participants were diagnosed with idiopathic PD by a clinical neurologist prior to participation according to the UK Brain Bank criteria for PD. Instead it provided information on patients personal evaluation of the most dominant motor symptoms at the time of examination; 2) The short version of the Questionnaire for Impulsive-Compulsive Disorders in Parkinson's Disease (QUIP), which is a validated screening instrument evaluating current and past impulsive and compulsive behaviors (ICBs) in PD [29, 30]. As the study design did not allow for clinical follow-up, we added items to the questionnaire regarding the daily amount of time spent on a given ICB, age at onset of the behavioral symptoms, force-choice categories of specific activities, and whether or not patients disclosed symptoms to a neurologist. These revisions to the QUIP were undertaken in close collaboration with Dr. Weintraub and did not interfere with the natural flow of the questionnaire [9]. We used the same cut-off point for the short version of the QUIP as recommended by Weintraub et al 2009 [29].

Statistical analyses

Data were analyzed using SPSS 24.0. We utilized frequency statistics and analysis of variance (ANOVA) to evaluate which ICBs are the most time consuming among Danish patients with PD reporting symptoms of either one or multiple ICBs, respectively.

In addition, chi-square analyses were used to evaluate gender differences in time consumption and ICB preferences and to assess which particular ICBs male and female patients were most likely to disclose to a neurologist or other healthcare professional.

Finally, we performed multivariate analysis of variance (MANOVA) to evaluate associations between ICBs and motor symptomatology in male and female patients, respectively and

subsequently conducted chi-square and binary logistics regression analyses to evaluate the impact of cardinal and non-cardinal motor symptoms on ICBs in men and women.

We noted no serious violations to the assumptions for any of the analyses.

Results

Descriptives

Four hundred and ninety patients participated in the study of whom 303 patients were men (61.8%). In total 318 patients were treated with levodopa either as monotherapy or in combination with dopamine agonist, which were administered to 239 patients. Nine patients received no kind of dopaminergic medication, and hence they were excluded from the analyses. Sample descriptives are summarized in **Table 1**.

Patients who did not wish to participate in the study were significantly older than participants ($p<.001$) and 49% hereof were men.

Insert Table 1 here

In total 176 patients (35.9% of total sample) reported symptoms of one (12.6% of total sample) or multiple ICBs (23.3% of total sample) sometime during the course of PD. Hereof, 131 men with a mean age of 66.69 years, a mean PD duration of 9.17 years, and a mean age at PD onset of 57.25 years relative to 45 women with a mean age of 70.28 years, a mean PD duration of 10.84 years, and a mean age at PD onset of 59.16 years. 14.9% of patients reported current behavioral symptoms at the time of examination. No significant differences in socioeconomic status were noted between PD patients with and without ICB symptoms. Results are summarized in **Table 2**.

Insert Table 2 here

Phenomenology and gender characteristics of hobbyism and punding

The most commonly reported ICBs in the current sample were hobbyism and punding, which considered together were present in 135 patients (27.5% of total sample). More specifically, 16.7% of patients displayed symptoms of hobbyism and 10.8% reported symptoms of punding. Overall, more male patients indicated symptoms of hobbyism and punding, however this difference only reached statistical significance for hobbyism ($p=0.001$). Moreover, 10.1% of patients with hobbyism and punding spend more than 5 hours daily on these compulsive behaviors, while 1.8%

spend more than 10 hours a day. No significant gender differences in time consumptions were found. However, frequency and chi-square analyses indicated that male and female patients engage differently in hobbyism and punding showing preferences for certain activities, e.g. excessive PC use, dismantling and repairing objects, tidying and cleaning. Results are illustrated in **Figure 1.** Furthermore, both male and female patients reporting ICBs described being pre-occupied with and feeling loss of control over the behavior and spending more time than wanted.

Insert Figure 1 here

With hobbyism and punding identified as common and time consuming behaviors in PD further analyses were conducted to explore whether patients systematically disclosed these compulsive behaviors to a healthcare professional. Overall, frequency analyses suggested that 4.8% of patients with symptoms of only one ICB relative to 26.3% of patients with multiple ICB talked to a professional about the behavioral alterations. Additionally, chi-square analyses revealed that males (87.9%) were more likely than females (12.1%) to address a professional. However, this difference only reached statistical significance for patients displaying multiple ICB ($\chi^2 = 3.98$, df =1, p=0.037). Furthermore, despite female patients reporting symptoms of different ICBs, they exclusively disclosed problems related to compulsive gambling, buying, and eating, and not hobbyism or punding, whereas male patients addressed behavioral issues across ICB subtypes. However, this gender difference only reached statistical significance for hobbyism ($\chi^2 = 5.430$, df =1, p=0.019) and compulsive sexual behavior, since no female patients reported any symptoms thereof.

Impact of motor symptomatology

To evaluate associations between ICBs and motor symptomatology in male and female patients we performed a between-groups MANOVA entering PD duration, age at PD onset, number of self-reported motor symptoms, dopamine agonist LEDD, and total LEDD as the dependent variables. Results indicated that relative to patients without ICBs, both male and female patients with ICBs were significantly younger at PD onset (p=0.000 and p=0.018, respectively). Younger age at time of examination (p=0.007) and longer PD duration (p=0.024) only reached statistical significance in men with ICBs, whereas only women with ICBs reported a higher number of motor symptoms (p=0.021). Results are summarized in **Table 2**.

Insert Table 2 here

Looking on hobbyism and punding alone, we noted that in both men and women age at PD onset (p=0.048 and p=0.037, respectively) and age at time of examination (p=0.028 and p=0.001, respectively) were significantly associated with symptoms of hobbyism, whereas punding was significantly associated with the total number of self-reported motor symptoms (p=0.005 and p=0.009, respectively).

In addition, chi-square analyses assessing the impact of cardinal (i.e. tremor, bradykinesia, rigidity, postural instability) vs. non-cardinal (i.e. freezing of gait, swallowing problems, dyskinesia, and pain and numbness) motor symptoms on ICBs in general significantly correlated non-cardinal symptoms and ICBs in both male and female patients (χ^2 = 7.3, df =1, p=0.005 and χ^2 = 3.5, df =1, p=0.045). A similar association was not found when considering hobbyism and punding separately. Furthermore, we performed binary logistic regressions entering any ICBs (all subtypes of ICBs considered together) as well as hobbyism and punding separately as dependent variable and cardinal and non-cardinal motor symptoms as the independent variable in separate models. Results indicated that non-cardinal motor symptoms predicted ICBs in male patients with PD (β=0.94, se=0.37, Exp(β)=2.57, p=0.011,) but not female patients, with non-cardinal motor symptoms increasing the odds of ICBs more than twice. No association was seen between cardinal motor symptoms and ICBs in neither men nor women.

Discussion

The current study was an epidemiological study designed to examine the subjective experience of hobbyism and punding among male and female patients with PD. Three clinically relevant research questions were addressed in this study to help guide early identification of ICBs in PD: i) do male and female patients with PD engage differently in hobbyism and punding?; ii) do male and female patients with PD disclose issues of hobbyism and punding to their doctor or neurologist equally often?; and finally iii) do different constellations of motor symptomatology predict hobbyism and punding differently in male and female patients with PD?

In general, the self-reported prevalence of ICB symptoms is high in the current sample with 35.9% of the total sample indicating behavioral symptoms of one or multiple ICBs sometime during the course of PD. This is comparable to previous findings in a Finnish sample [15] and to a recent Norwegian study [22]. However, the prevalence is a lot higher the prevalence presented by Weintraub et al. [8] based on a large American cohort of 3090 patients in which impulse control disorders were identified in only 13.6% of the sample. This could suggest that cultural differences may impact the prevalence of ICBs in PD, but at the same time it is important to mention that prevalence for current ICBs in this study was only 14.9% and thus comparable to the finding by Weintraub et al. [8]. Furthermore, these discrepancies could likely be related to the difference between reporting symptoms of ICBs as in the present study relative to actual diagnoses of impulse control disorders as in the study by Weintraub and colleagues [8].

The most commonly reported ICBs in the current sample were hobbyism and punding and results suggested that male and female patients with PD engage differently in hobbyism and punding activities. More specifically, the findings indicate, that gender might influence preferences for certain activities within these categories of compulsive behaviors. While more male patients spent time on hobbies such as dismantling and repairing objects and working on projects female patients engaged in punding-activities such as cleaning. Yet, gender did not clearly impact the time spent on hobbyism and punding in the sample. Both male and female patients describe hobbyism and punding as very time-consuming behaviors on which up to 10.6% of patients spent more than five hours each day. However, given the small number of female patients disclosing ICBs (n=45) in this sample it is difficult to perform detailed subgroup-statistics.

Additionally, we noted that both male and female patients reporting behavioral symptoms indicated being pre-occupied with and spending more time than they wanted on these compulsive behaviors. Also, they reported feeling loss of control over the specific activities in which they engaged. This might suggest a negative impact of hobbyism and punding in PD on subjective well-being, and recently, Kadastik-Eerme et al. [31] showed that non-motor symptoms in PD including impulse control disorders are associated with decreased health-related quality of life. Future studies are needed to assess the extent to which time consumption on and pre-occupation with ICB's affects quality of life and overall everyday functioning.

Addressing the second research question, results indicated that only few patients disclose any kind of ICB symptoms to a neurologist or other healthcare professionals. In the current sample only 12.1% of female patients disclosed ICB's to a clinician, and they only addressed certain behavioral

issues including compulsive gambling, buying, and eating but not hobbyism and punding. This discrepancy may be explained by gambling and buying being financially costly and over-eating directly observable rendering them more likely to be observed and addressed by relatives. However, future studies are needed to further explore and explain this difference.

Addressing the final research question, we noted that ICBs were significantly associated with younger age, earlier PD onset, longer PD duration, and more advanced motor symptomatology, which corresponds to previous findings on ICBs in PD [21, 7, 11, 9]. This likely resembles a more progressed disease, which is supported by prior findings linking ICBs to longer disease duration and the need for increased doses of medication [7, 9, 21], possibly reflecting more advanced stages of PD. However, in the current study hobbyism and punding appeared to be associated with distinct PD characteristics. While hobbyism was primarily related to age, punding was linked to more pronounced motor symptomatology. Possible associations between motor symptomatology and ICBs in PD have been addressed on several occasions but previous studies present conflicting results [22, 32, 12, 18, 8]. Interestingly, Gescheidt et al. [23] recently demonstrated that pathological gambling was associated with long-lasting dyskinesia. This association between compulsive behaviors involuntary movements in PD may reflect a continuum of motor and non-motor pathological expressions of PD which is likely mediated by the same underlying physiological mechanisms but acting through distinct basal ganglia circuits as suggested by Voon et al. [33]. In the current study, we likewise found that non-cardinal motor symptoms, including dyskinesia, correlates with ICBs in general. However, this association was only present in male patients in the current sample with non-cardinal motor symptoms doubling the likelihood of ICBs. Whether this is a result of the small number of female patients with ICBs or if it reflects a true gender difference cannot be determined in this study due to methodological limitations but it emphasizes the need for future research to explore this further. Yet, it is relevant to note, that recent findings suggest that PD is more prevalent among men than women, while female patients generally display more disabling motor symptoms and more rapid disease progression [24]. This offers a possible explanation for why relatively more female patients decide not to participate in the current study than male patients. If so, one might speculate whether or not a similar or perhaps even more pronounced association between advanced motor symptomatology and compulsive behaviors might be present among female patients with PD as well.

Some limitation needs mentioning. First, the overall sample in this study is relatively small and includes only few female patients. Focusing on the subgroup of patients with ICBs thus reduces

the sample size further and particularly the number of female patients with ICBs is small. Naturally, this affects the likelihood of detecting important group differences and clinical correlates of ICBs in especially female patients. However, the current sample is drawn from a representative sample of the Danish PD population and the distribution of male and female patients with and without ICBs in the sample could likely mirror the clinical reality of PD and ICBs affecting more males than females [34]. On the other hand, the gender distribution of participants and non-participants differ which indicates a potential risk of sampling-bias. Secondly, as female patients are reluctant to disclose behavioral complications to a healthcare professional it is likely that they hesitate to report behavioral symptoms in this study as well. Thirdly, data is based solely on self-report measures whereby it cannot be determined whether reported behavioral symptoms meet diagnostic thresholds. As the study was designed as an epidemiological survey, it did not allow for clinical follow-up. Additionally, as the QUIP has previously been shown to overestimate [27], it is possible that the prevalence of ICBs in this sample is inflated, perhaps in particular concerning hobbyism and punding. Similarly, the motor symptomatology was not evaluated by a standard neurological evaluation of disease severity using either UPDRS or Hoehn & Yahr. This is akin to other studies of ICBs in PD but poses a significant limitation to the field. However, as previously mentioned, it is important to note that all patients included in the study was diagnosed with idiopathic PD according to the UK Brain Bank criteria for PD by a clinical neurologist prior to participation.

Conclusion

In the current study, we examined PD patients' subjective evaluation of ICB symptoms and severity, including feelings of pre-occupation and loss of control based on self-report measures. We have presented findings that may have important clinical implications in terms of early identification and addressing of problematic behavioral side effects to the medical treatment of PD. The study provides detailed information about hobbyism and punding, which to date remain understudied. These findings contribute to a better understanding of the nature of these compulsive behaviors and may moreover offer guidance to clinicians by emphasizing not only the need for regular screening for ICBs in PD but also the need for neurologists and other healthcare professionals to explicitly ask patients about behavioral alterations and time consumption to properly evaluate the presence and severity thereof. This is particularly important since many patients, perhaps especially women, may not address these issues themselves or underestimate the severity thereof [28]. Furthermore, the reluctance amongst women to disclose ICBs, despite

activities being equally time consuming and problematic in men and women, stress the relevance of including close relatives as informants when screening for and potentially managing ICBs. Finally, findings of advanced motor symptomatology, and perhaps non-cardinal symptoms in particular, being related to ICBs in PD cautiously suggest that motor symptomatology could play a role in the non-motor manifestations of PD as well, and thus underlines the relevance for future studies to more carefully evaluate motor characteristics when assessing behavioral complications to the treatment of PD.

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Conflicts of interest

The authors have no conflict of interest to declare.

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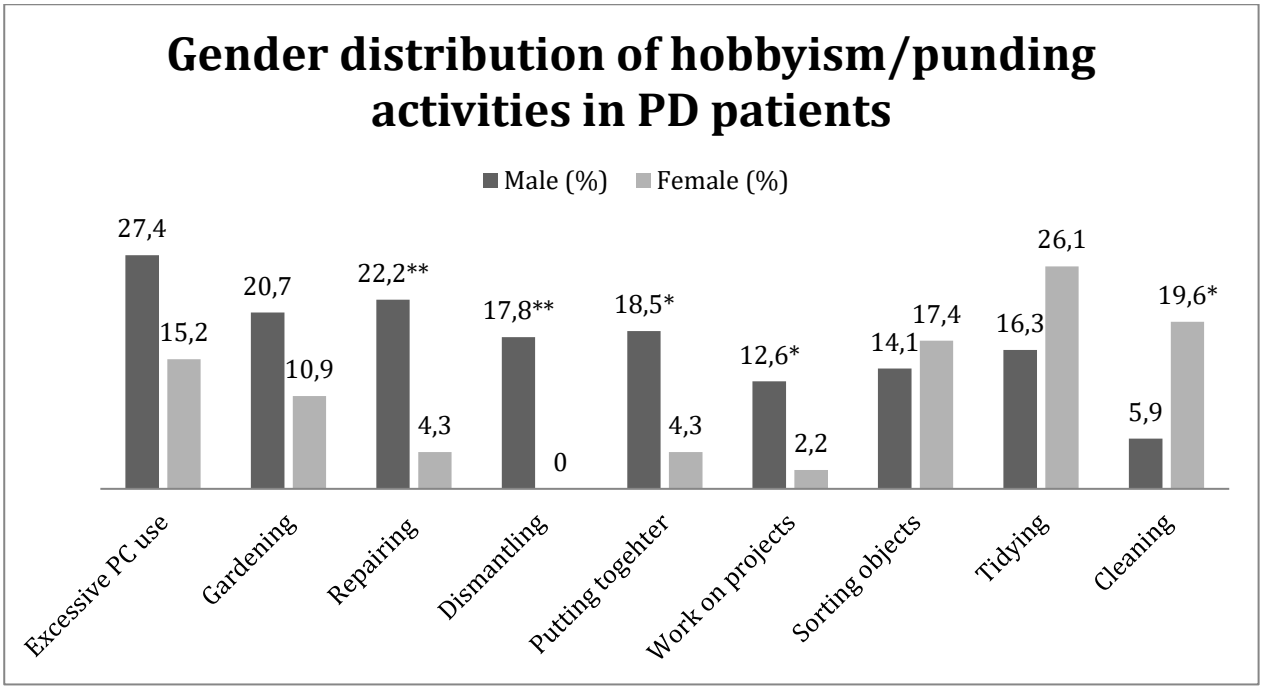
Figure 1



** = significant at p<.01
* = significant at p<.05.

Figure 1 illustrates the gender distribution across the most common hobbyism/punding activities given in percent of male and female patients with ICBs, respectively.

Table 1

Table 1 summarizes descriptives on the total sample.

	Mean	Min.	Max.	SD
Age (years)	70.9	42	92	9.3
PD duration (years)	8.2	<1.0	43.0	6.3
Age at PD onset (years)	62.5	30.0	91.0	10.9
Total LEDD (mg/day)	619.1	18.0	1820.0	349.2
DA LEDD (mg/day)	127.6	0.0	562.5	143.3
Number of motor sxs [a]	5.0	0.0	10.0	2.4

PD = Parkinson's disease. LEDD = Levodopa equivalent daily dose. DA LEDD = Dopamine agonist levodopa equivalent daily dose. Sxs = symptoms. [a] number of self-reported motor symptoms based on 1-10 yes/no questions.

Table 2
MANOVA on PD variables in male and female patients with and without ICBs.

Male patients w. ICBs	**Mean**	**SD**	**Male patients wo. ICBs**	**Mean**	**SD**
Age (years)	67.3**	8.8	Age (years)	70.8	8.9
PD duration (years)	8.9*	6.6	PD duration (years)	7.0	5.1
Age at PD onset (years)	58.4**	10.2	Age at PD onset (years)	63.8	10.4
Number of motor sxs[a]	5.3	2.3	Number of motor sxs[a]	4.7	2.4
DA-LEDD (mg/day)	155.9	132.1	DA-LEDD (mg/day)	142.2	150.3
Total LEDD (mg/day)	675.4	413.6	Total LEDD (mg/day)	602.1	325.3
Female patients w. ICBs	**Mean**	**SD**	**Female patients wo. ICBs**	**Mean**	**SD**
Age (years)	69.7	9.9	Age (years)	72.9	8.9
PD duration (years)	10.5	9.7	PD duration (years)	7.9	6.4
Age at PD onset (years)	59.2*	13.1	Age at PD onset (years)	65.0	10.2
Number of motor sxs[a]	5.8*	2.5	Number of motor sxs[a]	4.6	2.1
DA-LEDD (mg/day)	117.7	141.6	DA-LEDD (mg/day)	111.8	139.3
Total LEDD (mg/day)	652.2	3334.0	Total LEDD (mg/day)	571.2	289.3

DA = Dopamine agonist. LEDD = Levodopa equivalent daily dose. PD = Parkinson's disease. Sxs = symptoms. [a] number of self-reported motor symptoms based on 1-10 yes/no questions. W. = with. WO. = without. * = $p<0.05$. ** = $p<0.01$.