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Short communication

Impulsive and compulsive behaviors in Parkinson's disease: Impact on quality of and satisfaction with life, and caregiver burden

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ABSTRACT

Introduction: To disentangle the association between impulsive and compulsive behaviors (ICBs), health-related quality of life (HRQOL), satisfaction with life (SwL), and caregiver distress in dyads of people with Parkinson's disease (PwP) and caregivers.

Methods: Data used in this study were obtained from the ongoing Norwegian ParkWest study, a population-based longitudinal cohort study of the incidence, neurobiology and prognosis of PD in Western Norway. One hundred and one dyads of PwP free of dementia and their caregivers were included 5 years after PD diagnosis and inclusion in the ParkWest study. Standardized clinical rating scales were used to evaluate ICBs, HRQOL, SwL and caregiver distress.

Results: Of 101 PwP-caregiver dyads, self-reported ICBs were seen in 33% of PwP and only caregiver-reported ICBs in 12% of PwP. PwP-reported ICBs were associated with poorer HRQOL and SwL, whereas ICBs reported by caregivers only were associated with increased caregiver distress, but not poorer HRQOL or SwL in PwP.

Conclusions: ICBs have adverse effects on HRQOL, SwL and caregiver distress. These findings underpin the need for proper identification and management of ICBs in PwP.

1. Introduction

Impulsive and compulsive behaviors (ICBs) are common among people with Parkinson's disease (PwP) [1]. These non-motor symptoms are characterized by difficulties resisting the impulse, drive or temptation for a behavior, and may have adverse effects on the quality of life of PwP and potentially severe interpersonal consequences [2–5]. In PD, ICBs are closely associated with the use of dopamine agonists, with the risk being most prominent in younger PwP, early onset PD, male gender, tobacco use or history with other addictions [1].

Due to the association between ICB development and dopaminergic treatment [1], frequent screening of these behaviors is recommended. However, screening is not always straightforward in clinical practice, as it relies on the self-assessment of PwP who may lack insight into the frequency, severity and consequences of their own behavior [6,7]. ICBs may also function as a coping strategy for the existential and personal crises that often follow the diagnosis of a chronic disease [7]. Affected PwP may also avoid disclosing these symptoms to their physician, family and caregivers, due to the stigma and interpersonal consequences that may follow disclosing these behaviors. Caregivers may carry the burden of these behavioral disorders, especially if the behaviors are pronounced, but not acknowledged, by the person with ICBs. Thus, the personal and interpersonal consequences of ICBs may differ widely between PwP and caregivers. In this study, we therefore explored the impact of ICB presence on the quality of and satisfaction with life in PwP, and caregiver distress.

2. Methods

2.1. Study design and participants

We used data from the ongoing Norwegian ParkWest project, a population-based longitudinal study of incident PD. Details of the case ascertainment and diagnostic procedures to recruit a population-representative PD cohort have been published elsewhere [8]. In short, 212 newly diagnosed, drug naïve PwP were recruited from four

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counties in Norway between 2004 and 2006, and followed prospectively by movement disorder neurologists. As previously reported, screening for ICBs was first introduced after five years of follow up, where 124 PwP remained in the study [9]. In this cross-sectional study, complete datasets from 101 PwP free from dementia and their caregivers was used. Among caregivers, 73.3% were spouses, 19.8% were 1st degree relatives, and 6.9% categorized as "other caregivers". The study was approved by the Regional Committee for Medical and Health Research Ethics, Western Norway. Signed written informed consent was obtained from all participants.

2.2. Assessments

A standardized examination program was administered by trained members of the ParkWest study group. Information regarding demographic variables, lifestyle factors, clinical history, and medication was obtained from semi-structured interviews. Motor severity and disease stage were assessed by the Unified PD Rating Scale (UPDRS) and the Hoehn and Yahr staging. Global cognitive function was evaluated using the Mini-Mental State Examination (MMSE), and depressive symptoms were evaluated using the Montgomery and Asberg Depression Rating Scale (MADRS). The self-report and informant version of the Questionnaire for Impulsive-Compulsive Disorders in PD – Short form (QUIP) was used to assess ICBs in PwP [10]. We categorized PwP as "No ICBs" when neither patients nor caregivers reported ICBs on QUIP, as "Self-reported ICBs" when PwP reported ICBs on QUIP, and as "Only caregiver-reported ICBs" when caregivers, but not PwP reported ICBs on QUIP. Due to the limited number of cases where PwP and caregivers (N = 9) agreed in their rating of ICBs, these cases were included in the "Self-reported ICBs".

The 36-item RAND Health Status Inventory (RAND-HSI), a generic self-report measure of functional health and well-being recommended for use in PwP, was used to measure health-related quality of life (HRQOL) [11,12]. The measure evaluates eight domains of HRQOL, and includes three composite scores; physical health, mental health, and global health. For this study, the Global Health Composite (GHC) score of the RAND-HSI was used. In addition, the 5-item Satisfaction With Life Scale (SWLS) was used to measure the life satisfaction component of subjective well-being [13,14]. Caregiver distress was measured using the Relatives' Stress Scale (RSS), a 15-item self-report measure commonly used to assess caregiver distress in geriatric patient populations [15,16]. RSS is scored on a 5-level Likert scale, ranging from 0 = "not at all" to 4 = "to a high degree", and a sum-score can be derived as a measure of the level of overall caregiver stress.

2.3. Statistical methods

All statistical procedures were performed using IBM SPSS Statistics for Windows, Version 24.0. Armonk, NY: IBM Corp. Univariate group differences in demographic and clinical variables were explored using general linear modeling (GLM). Multivariate GLM was used to investigate the relationship between ICB status and scores of HRQOL, SwL, and caregiver distress. In these analyses, separate models with RAND-HSI GHC, SWLS and RSS scores as dependent variables were performed. In each model, age, sex, duration of PD (years), UPDRS motor score, MADRS score, and ICB category ("No ICBs" was used as the reference category) were entered as independent variables. Simple planned contrasts were estimated to further differentiate between the groups in the multivariate analyses. Two-tailed p values < 0.05 were considered statistically significant.

3. Results

Demographic and clinical characteristics of the PwP are presented in Table 1. Overall, ICBs were reported by either PwP or caregivers in 45 (44.6%) of the 101 cases, whereas 56 (55.4%) cases had no ICBs.

Compared to PwP without ICBs, PwP with self-reported ICBs were significantly younger (B = −5.8; p = 0.003; 95% CI -9.5 to −2.0) and had higher MADRS (B = 2.9, p = 0.003; 95% confidence interval [CI] 1.0 to 4.8) and RSS scores (B = 6.6, p = 0.001; 95% CI 2.9 to 10.4), but lower RAND-HSI GHC (B = −8.1, p = 0.003; 95% CI -13.4 to −2.8)) and SWLS (B = −4.5, p = 0.001; 95% CI -7.2 to −1.8) scores. In contrast, PwP with only caregiver-reported ICBs had higher RSS scores (B = 8.6, p = 0.002; 95% CI 3.1 to 14.1) than PwP without ICBs, but did not differ on other measures.

The results from the GLM analyses are shown in Table 2. There was a negative association between PwP-reported ICBs and RAND-HSI GHC (B = −5.3, p = 0.016, 95% CI -9.5 to −1.0) and SWLS (B = −3.7, p = 0.014, 95% CI -6.6 to −0.7) scores, and a positive association between only caregiver-reported ICBs and RSS scores (B = 8.9, p = 0.001, 95% CI 3.6 to 14.2), independent of potential confounders.

4. Discussion

In this study, we demonstrate that PwP-reported ICBs are associated with poorer quality of and satisfaction with life in PwP themselves, but not increased caregiver burden. In contrast, only caregiver-reported ICBs were associated with increased levels of distress among caregivers, but not poorer quality of and satisfaction with life in PwP. This highlights the importance of proper identification and management strategies of ICBs in PwP and their caregivers.

To our knowledge, this is so far the first investigation of both subjective well-being and quality of life in PwP with and without ICBs. In order to investigate the full range of these modalities, we included the RAND-HSI and SWLS. Although these measures often correlate, they represent different modalities of quality of life and well-being, and may be influenced differently by motor and non-motor symptoms of PD. In our study, both measures were associated with self-reported ICBs after adjusting for potential confounders. Although previous studies have reported an associated between ICBs and HRQOL in PwP [2,4], this association may have been an artifact of increased depressive symptoms in PwP with ICBs [3]. In this study, we demonstrate an independent effect of ICBs on HRQOL and SwL even after adjustment for depressive symptomatology. Interestingly, the effect on HRQOL and SwL was only evident in PwP-reported ICB cases, but not in ICB cases reported by caregivers only.

Our data, however, identifies increased caregiver distress among PwP with only caregiver-reported ICBs. This finding highlights the importance of "insight" for PwP with ICBs, and mirrors a common clinical observation; i.e. caregiver distress is most prominent when the caregiver consider the behavior of the PwP as troublesome, but the PwP does not agree or have insight into the severity of his or her behavior. Although this finding has important clinical implications, it may be confounded by other important clinical factors not included in this study, such as cognitive deficits or depression [17,18]. We did not find significant differences on MMSE or MADRS in our data, both depression and cognitive deficits have impact on self-evaluation, insight and ability to self-report [19]. This is supported by evidence from a recent clinical trial of cognitive behavioral therapy for ICBs, where a reduction of severity of ICBs was associated with a decrease in the severity of depressive symptoms [20].

These findings are relevant for both clinical practice and future research. The negative effect of ICBs on subjective well-being argue for the development of clinical practices that aid PwP in addressing ICBs with their neurologist. Strategies such as the involvement of caregivers in the long-term management of PD, and the use of full diagnostic interviews with regards to ICBs, may increase the probability of patients disclosing ICBs during clinical examinations [6]. Furthermore, continued development of non-pharmacological treatment strategies that can assist PwP and their caregivers in managing ICBs and its consequences is necessary. This includes interventions that reduce the risk of relational and marital crises that often follow ICBs. Cognitive

Table 1
Characteristics of PwP stratified according to ICB group.

Characteristics	All (N = 101)	No ICBs (N = 56)	Self-reported ICBs (N = 33)	Only caregiver-reported ICBs (N = 12)	P-value of overall model
Male, n (%)	64 (63.4)	33 (58.9)	25 (75.8)	6 (50.0)	0.295
Age, y	71.2 (9.0)	73.7 (9.3)	***67.9 (7.8)***	69.0 (7.6)	**0.009**
Duration of PD	7.2 (1.6)	7.1 (1.8)	7.4 (1.5)	7.3 (0.9)	0.655
UPDRS motor score	23.2 (10.8)	23.1 (11.0)	24.8 (10.9)	19.3 (9.1)	0.330
Hoehn and Yahr stage	2.2 (0.6)	2.2 (0.7)	2.2 (0.6)	2.1 (0.3)	0.770
Total LED	589.2 (335.2)	509.1 (311.6)	***746.5 (345.4)***	536.6 (281.4)	**0.004**
Levodopa dose	345.5 (304.6)	324.1 (300.4)	392.4 (337.8)	312.5 (223.7)	0.556
Dopamine agonist use, n (%)	64 (63.4)	28 (50.0)	***29 (87.9)***	7 (58.3)	**0.003**
Dopamine agonist LED[a]	189.6 (183.0)	294.0 (166.1)	293.0 (133.4)	291.3 (124.1)	0.999
MMSE score	27.7 (2.7)	27.2 (3.2)	28.4 (1.7)	28.3 (1.7)	0.091
MADRS score	3.7 (4.5)	2.8 (3.8)	***5.7 (5.2)***	2.6 (4.0)	**0.008**
RAND-HSI GHC score	40.7 (12.5)	43.6 (12.5)	***35.5 (12.5)***	41.6 (8.5)	**0.011**
SLWS score	24.6 (6.4)	26.3 (6.5)	***21.8 (6.2)***	24.9 (4.4)	**0.005**
RSS score	9.7 (9.3)	6.5 (7.4)	***13.1 (9.6)***	***15.1 (9.3)***	**< 0.001**

Data are mean (SD) unless otherwise indicated.
PwP = People with Parkinson's disease; PD = Parkinson's disease; ICBs = Impulsive and compulsive behaviors; UPDRS = Unified Parkinson's Disease Rating Scale; LED = Levodopa equivalent dosage; MMSE = Mini-Mental Status Examination; MADRS = Montgomery and Asberg Depression Rating Scale; RAND-HSI GHC = 36-item RAND Health Status Inventory Global Health Composite score; SWLS = Satisfaction with Life Scale; RSS = Relatives Stress Scale.
Bold indicates p-values < 0.05; ***Bold italics*** indicates significant differences (p-value < 0.05) from the reference category "No ICBs".
[a] Mean DA LED based on DA users only (N = 64 for entire group; N = 28 for no ICB group; N = 29 for self-reported ICB group; N = 7 for only caregiver reported ICB group).

Table 2
Results from separate general linear models of different quality of and satisfaction with life measures.

Variable	RAND-HSI GHC		SWLS		RSS	
	B[b]	P-value	B[b]	P-value	B[b]	P-value
Age	−0.2	0.060	0.1	0.578	−0.1	0.307
Male[a]	4.3	**0.031**	**3.2**	**0.020**	**5.0**	**0.009**
Duration of PD	0.3	0.554	−0.2	0.621	0.6	0.298
UPDRS motor score	**−0.3**	**0.001**	−0.1	0.227	0.1	0.289
MADRS score	**−1.5**	**0.001**	**−0.3**	**0.026**	**0.4**	**0.047**
Patient-reported ICB[b]	**−5.2**	**0.016**	**−3.7**	**0.014**	3.7	0.075
Only caregiver-reported ICB[b]	−4.0	0.152	−1.2	0.546	**8.9**	**0.001**

PD = Parkinson's disease; UPDRS = Unified Parkinson's Disease Rating Scale; MADRS = Montgomery and Aasberg Depression Rating Scale; RAND-HSI GHC = 36-item RAND Short Form Health Survey Global Health Composite score; SWLS = Satisfaction with Life Scale score; RSS = Relatives Stress Scale score. **Bold** indicated p-values < 0.05.
[a] Compared to female (reference category).
[b] Compared to "no ICB"-group (reference category).

behavioral therapy (CBT) have shown promise as a treatment that both benefit PwP and their caregivers [20].

The major strengths of this study are the population-based design, the use of multiple validated scales of life satisfaction, and the inclusion of caregivers in the evaluation of ICBs. Limitations include the cross-sectional data, the limited size of ICB groups not allowing for in-depth analyses, and the use of MMSE as a measure of global cognitive functioning. However, this study is exploratory in nature, and our findings should therefore be replicated in larger cohorts of PwP-caregiver dyads, including a larger array of possible neuropsychiatric correlates. Future studies should also aim to further differentiate between individual ICBs and their effect on QoL and caregiver distress in PwP.

Search terms

Parkinson's disease, impulse control disorders, quality of life, satisfaction with life, caregiver burden.

Author disclosures

Nothing to report.

Contributors

AHE: study conception and design, analysis and interpretation of data, writing of the first draft. GA: study concept and design, acquisition of data, critical revision of the manuscript, study supervision. OBT: study concept and design, acquisition of data, critical revision of the manuscript, study supervision. KFP: study concept and design, acquisition of data, analysis and interpretation of data, critical revision of the manuscript, study supervision. All authors have approved the submitted manuscript.

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The authors have nothing to report.

Research data

Anonymized data are available upon reasonable request. Please contact the corresponding author, or use contact information on www.parkwest.no for details regarding conditions for reuse and data access.

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