

## Feeling of presence in Parkinson's disease

Gilles Fénelon,<sup>1,2,3</sup> Thierry Soulas,<sup>4</sup> Laurent Cleret de Langavant,<sup>1,2,3,5</sup> Iris Trinkler,<sup>2,3</sup>  
and Anne-Catherine Bachoud-Lévi<sup>1,2,3,5</sup>

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<sup>1</sup>AP-HP, Groupe Hospitalier Henri-Mondor, Service de neurologie, Créteil, France;

<sup>2</sup>INSERM U955, Equipe 1, Institut Mondor de Recherche Biomédicale, Créteil, France;

<sup>3</sup>Département d'Etudes Cognitives, Ecole Normale Supérieure, Paris, France;

<sup>4</sup>Université Paris-Descartes, Laboratoire de Psychopathologie et Processus de Santé, EA 4057, Boulogne, France;

<sup>5</sup>Université Paris-Est, Faculté de Médecine, UMR-S 955, Créteil, France.

Corresponding author:

Dr Gilles Fénelon

Service de neurologie

CHU Henri Mondor

94010 – Créteil cedex

France

Tel: 33 1 49 81 43 13

Fax: 33 0 19 81 23 26

E-mail: gilles.fenelon@hmn.aphp.fr

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## ABSTRACT

**Background.** A feeling of presence (FP), ie the vivid sensation that somebody (distinct from oneself) is present nearby, is commonly reported by patients with Parkinson's disease (PD) but its phenomenology has not been described precisely. The objective of this study was to provide a detailed description of FP in PD and to discuss its possible mechanisms.

**Patients and methods.** We studied 52 non-demented PD patients reporting FP in the preceding month (38 consecutive outpatients and 14 inpatients). FP characteristics were recorded with a structured questionnaire. The outpatients with FP were compared to 78 consecutive outpatients without FP.

**Results.** About half the patients said they recognized the "identity" of the presence. More than 75% of patients said the FP were not distressing, were short-lasting, were felt beside and/or behind the patient, and occurred while indoors; most patients checked for a real presence but their insight was generally preserved. In 31% of cases the patients had an unformed visual hallucination simultaneously with the FP. A higher daily levodopa-equivalent dose and the presence of visual illusions or hallucinations were independently associated with FP.

**Discussion.** Although FP is not a sensory perception, projection of the sensation into the extrapersonal space, along with the frequent co-occurrence of elementary visual hallucinations and the strong association with visual hallucinations or illusions, support its hallucinatory nature. FP may be viewed as a "social" hallucination, involving an area or network specifically activated when a living being is present, independently of any perceptual clue.

## INTRODUCTION

The feeling of presence (FP) refers to the vivid sensation that somebody (distinct from oneself) is present nearby, when no one is actually there, in the absence of sensory clues revealing a presence. Such sensations have given rise to numerous literary and religious accounts. The first description of FP by a psychologist was probably that of William James in 1902: "*It often happens that an hallucination is imperfectly developed: the person affected will feel a 'presence' in the room, definitely localized, (...) and yet neither seen, heard, touched, nor cognized in any of the usual 'sensible' ways.*" [1] Jaspers [2] described the same phenomenon in 1913 under the name *leibhaftige Bewusstheit*: "*There are patients who have a certain feeling (in the mental sense) or awareness that someone is close by, behind them or above them, someone that they can in no way perceive with the external senses, yet whose*

*actual/concrete presence is directly/clearly experienced*" (translation by Koehler and Sauer [3]). Jaspers distinguished FP in normal subjects from those occurring in patients with *dementia praecox* (ie schizophrenia) who lacked insight and incorporated the FP into a delusion.[2] Critchley later identified a variety of causes, including neurological conditions such as epilepsy, for this "*sort of rudimentary hallucination*".[4] This sensation has been described as an idea, impression, sense or feeling of presence. The term "extracampine hallucinations" has been wrongly equated to FP.[5] Bleuler called "extracampine" a type of visual or tactile hallucination reported by patients with psychiatric disorders and occurring outside the limits of the corresponding sensory field.[6] For example, a patient felt, on his skin, mice running on a wall, while another one "saw" birds or persons in a garden while seated in a room with his back to the window. Thus, extracampine hallucinations have a sensory component that is typically absent in FP.

FP may be experienced by normal subjects, either without any facilitating factor, or more commonly following bereavement. About half of all persons who have lost their spouse report FP of the deceased in the years that follow.[7] There are also anecdotal reports of FP occurring in extreme circumstances, for example during shipwrecks or high-altitude mountain climbing.[4] FP are also experienced in several pathological situations, including schizophrenia and "schizotypal personality disorder",[3, 8] Parkinson's disease (PD),[9, 10] and dementia with Lewy bodies.[11, 12] FP may also occur as an epileptic aura,[13-17] or following brain damage.[18, 19] Finally, FP is a common form of hypnagogic and hypnopompic hallucination, whether it occurs in normal subjects or in the course of narcolepsy, and whether in isolation or simultaneously with sleep paralysis.[20-22]

To our knowledge, FP associated with PD was not described in the prelevodopa era. In the proceedings of a 1970 symposium, de Ajuriaguerra mentioned that patients with PD or post-encephalitic parkinsonism sometimes had "the simple impression of a presence", but he did not specify whether or not the patients received the recently available levodopa.[23] After dopaminergic treatment became available, FP were recognized as common,[24] and then systematically investigated in cross-sectional studies, along with hallucinations and other "minor" psychotic symptoms of PD, such as visual illusions.[9, 10, 25] FP is now accepted as part of the spectrum of psychotic symptoms in PD and is included in the new diagnostic criteria for PD-associated psychosis proposed by an NINDS-NIMH work group.[26] On applying these criteria to 116 consecutive patients with PD, we found that FP was experienced by 34% of patients and was the most prevalent psychotic symptom.[25] Similarly, Williams *et al.* recorded FP in 40% of 115 consecutive PD patients.[10] However,

the phenomenology of FP has not yet been described systematically. The main goal of this study was therefore to provide a detailed description of FP in PD and, on the basis of its phenomenology, to start uncovering the possible mechanisms of this intriguing phenomenon.

## **METHODS**

### **Subjects**

Fifty-two PD patients who had experienced FP in the preceding month participated in the study. PD was diagnosed according to the UK Brain Bank criteria.[27] Patients had to be fluent in French and, if cognitively impaired, to be able to understand and answer the questionnaire. Patients were considered to have FP if they answered "yes" to the following question: *"do you sometimes feel the presence of somebody when no-one is there?"* The examiner made clear the difference between a formed visual hallucination (VH) of a person and an FP. Thirty-eight of the 52 patients were identified among 116 consecutive outpatients,[25] while the other 14 patients were inpatients. The 38 outpatients with FP were compared with the 78 patients from the same population who reported having no FP in the preceding month.

### **Procedures**

To investigate the phenomenological characteristics of FP, we designed a structured questionnaire based on the general characteristics of hallucinatory phenomena in PD[26] and on previous clinical experience. The questionnaire included 16 items distributed in 6 sections, namely content, temporal characteristics, spatial characteristics, insight and repercussions, association with visual experience, and associated psychotic symptoms. Most of the items are self-explanatory, and some are commented on below. Insight was considered absent if the patient believed in the reality of a presence even after checking for and not finding a visible presence. The "influence" item explored the belief that the presence could influence the patient's thoughts or actions (excluding the brief action of checking for a real presence), by asking: "do you think that the "presence" influences how you think or act?" We had previously noticed that some patients reported a vague visual impression concomitant with the sense of presence, and/or would spontaneously use terms of imagery in reporting their experience (e.g. "I see a man behind me").[9] We therefore looked for elementary VH and, if present, ensured that they had none of the visual characteristics of a person (recognizable features of a body, face or clothes). We also recorded the spontaneous use of imagery terms in the time frame of the questionnaire. The patients with FP (n=52) and the outpatients free of FP (n=77) also answered a previously published structured questionnaire on hallucinations in

visual and other sensory modalities, visual illusions (ie the misinterpretation of a real external stimulus), and delusions.[25] Their demographic and PD-related data were recorded. The levodopa-equivalent daily dose was calculated using published equivalencies.[28] The use of dopaminergic agonists, amantadine, anticholinergics, psychoactive drugs (antidepressants, anxiolytics, and/or hypnotics) and clozapine was recorded. Patients with FP completed a brief cognitive test, the Mini Mental Parkinson (MMP, maximum score 32, lower scores indicating poorer cognitive status)[29], and the French version of the Beck Depression Inventory II (BDI-II, maximum score 63, higher scores indicating more severe depressive symptoms).[30] BDI-II scores were analyzed both as a continuous variable and as a dichotomous variable, using a 19-point cut-off for clinical depression.

### **Statistical analysis**

Fisher's two-tailed exact test and chi-squared test were used to examine the statistical significance of relations between categorical variables. When the whole cohort was divided into two samples on the basis of a categorical variable, independent *t* tests were used to compare the means of interval variables. Multivariate analysis used stepwise logistic regression and included all statistically significant covariates ( $p < 0.05$ ). Continuous variables were dichotomized around the median. SPSS 18.0 software for Windows was used for all analyses.

## **RESULTS**

### **Characteristics of FP**

The demographic and clinical characteristics of the 52 patients with FP are shown in Table 1, and the characteristics of the FP are shown in Table 2. One patient felt the presence of a former pet dog, while all the other patients felt a human presence, which was unidentified in most cases. Patients who felt the presence of a deceased relative were not more depressed than patients with other types of FP, as shown by the lack of difference between the two groups in the mean BDI-II scores (respectively 21.0 and 21.2,  $t(46)=0.08$ ,  $p=0.932$ ) and in the proportion of patients with scores higher than 19 (51% vs 69%,  $p=0.338$ ).

In a few cases the presence was that of a close relative (commonly the spouse) who had just left the room, leaving the patient alone. More commonly the FP occurred while the patient was alone, but in circumstances in which he or she used to being in the company of the spouse; for example, while sitting on a sofa watching television, the patient would feel the presence of the spouse beside him/her. There was no predominant schedule in most cases. In only 3 cases was the FP clearly hypnagogic or hypnopompic, with no associated sleep

paralysis. In about 80% of cases the sensation was brief (lasting a few seconds) and recurred more than once a week. FP had been present for a mean of  $2.9 \pm 4.2$  years, but the patients were vague about the onset of the phenomenon.

In 58% of cases the presence was felt beside (and often slightly behind) the patient, as frequently on one side as on the other. Patients who felt the presence beside or behind them felt it in close proximity. However, in 6 cases the presence was felt as remote, outside the house in one case and in another room in 5 cases. In the 47 patients in whom the FP tended to predominate on one side, there was no association between the side of the presence and the predominant side of motor signs ( $p=0.335$ , Fisher's exact test). The FP was often spontaneously described as static; none of the patients mentioned a moving presence.

Insight was preserved in 77% of cases. Compared with patients with preserved insight, patients with a lack of insight had a higher mean BDI-II score (respectively 19.8 and 25.4,  $t(46)=2.26$ ,  $p=0.029$ ), and tended to have lower mean cognitive scores in the MMP (respectively 26.2 and 22.8;  $t(50)=2.02$ ,  $p=0.064$ ). Most patients checked for a real presence, usually by looking to the side or behind, and occasionally by scanning the room more intently. One patient occasionally woke his wife when he felt a presence outdoors. The phenomenon was described as unpleasant or worrisome in 38% of cases, but only four patients (8%) said they felt really scared or threatened. Conversely, four patients, all of whom felt the presence of a relative (deceased in three cases), described the FP as pleasant, and even protective in two cases.

Few patients spontaneously used terms of imagery to describe the FP. However, nearly one-third said they saw an unformed "shadow" or "mist" associated with the sense of presence. This shadow never took the form of a human body or part of a body. For example, a 64-year-old woman who had had PD for 16 years felt the presence of her beloved deceased grandmother; she saw, on her left side, "something like a shadow, a dense steam, a large rectangle with no head, no body and no feet but trying to look at me, turning towards me". She would feel scared and look away.

**Associated symptoms.** FP was commonly associated with other non concomitant psychotic symptoms, including visual illusions, hallucinations (mostly formed VH), and occasionally delusions. One patient described formed VH and FP with similar characteristics. This 65-year-old man had had PD for 8 years and had moderate cognitive impairment. Sometimes he experienced a VH of a woman, whom he saw distinctly from head to foot, and at other times he felt the presence of a woman but had no accompanying visual sensation. In both cases he referred to an unidentified woman on his right side, and felt the need to check for a real

presence by turning his head, which caused the phenomenon to cease. His VH occurred electively in the morning, while washing or shaving, while the FP occurred only at sleep onset during an afternoon nap. Patients with associated hallucinations had lower cognitive scores on the MMP than patients who had FP alone or combined with another minor psychotic symptom (respectively 24.2 and 27.4,  $t(50) = 3.24$ ,  $p=0.002$ ). Patients with associated hallucinations also had a longer mean disease duration (13.0 and 9.2 y,  $t(50) = 2.10$ ,  $p=0.04$ ). In contrast, they did not differ in terms of the BDI score, the mean L-dopa equivalent daily dose, or the use of psychoactive drugs.

### **Comparison of patients with and without FP**

We then compared the demographic and clinical characteristics of the consecutive unselected outpatients with FP (n=38) and without FP (n=78). Not all the patients without FP completed the MMP and BDI-II, and the results of these tests were therefore not included in this analysis. The characteristics of the two groups are shown in Table 3. Multivariate analysis identified three independent factors predictive of FP: higher levodopa-equivalent daily doses (>750 mg), VH, and visual illusions (Table 4). We found no link between the predominant side of parkinsonism and the existence of FP. We also compared the 15 outpatients with isolated FP, i.e. without visual illusions, hallucinations or delusions, with the 53 outpatients who had no psychotic symptoms. No significant differences were found (data not shown), but the patients with isolated FP tended to have higher levodopa-equivalent daily doses (898 vs 661 mg,  $p=0.053$ ) and more frequent use of psychoactive drugs (8 vs 13 patients,  $p=0.055$ ).

## **DISCUSSION**

### **Phenomenology of FP**

This study provides the first clinical description of FP associated with PD. The characteristics of FP show some variability. The “identity” of the presence was not always recognized. The emotional experience of FP was variable from one patient to another: FP was occasionally unpleasant but rarely distressing. No predominant schedule was identified. However, the following characteristics were present in at least three-quarters of the patients: FP was short-lived (seconds) and occurred several times per week, indoors; the “presence” was felt beside and/or behind the patient; the patient felt the need to check for a real presence but insight was preserved in most cases. Even with lost insight, FP in PD patients typically lacked the delusional component characteristic of schizophrenia or other psychotic disorders.[2,8] When the FP was located beside the patient, there was no predominant side and no association between the side of the presence and the predominant side of PD motor signs, suggesting that

hemispheric specialization plays no part in the genesis of FP in this setting. This contrasts with the previous findings of Persinger, who found that 22 of 28 patients reporting FP after closed head injury felt the presence on their left.[18] Conversely, Brugger *et al.*, in a review of 27 cases of FP secondary to various causes, found a slight predominance of the right side.[19]

Two clinical characteristics of FP observed here have not previously been described. The first is the feeling of a persistent or recurrent presence of a person who had just left the scene. We propose to call this phenomenon *palinparousia*, from the Greek *palin*, “again”, and *parousia*, “presence”, by analogy with “palinopsia.” The temporal variety of palinopsia consists of the persistence, or the reappearance after a few seconds or minutes, of the image of an object after the subject has stopped looking at the object.[31] Another interesting feature of FP is the presence, in about one-third of cases, of an unformed VH which, although it has no recognizable human visual features, is associated with the FP, suggesting in these cases the activation of a neural network involving visual areas.

### **Factors associated with FP**

PD patients with and without FP could not be compared for cognitive (MMP) and depression (BDI-II) scores. Despite this limitation, we identified some factors relevant to the discussion of the pathophysiology of FP. A higher daily levodopa-equivalent dose emerged as an independent predictor of FP. In contrast, in most previous studies the mean levodopa or levodopa-equivalent dose did not differ between patients with and without VH,[32] suggesting a specific facilitating role of dopaminergic therapy in FP. Besides, visual illusions and VH were independently predictive of FP, suggesting shared mechanisms (see below).

### **FP as a hallucinatory phenomenon**

Our phenomenological data provide some insights into the nature of FP in PD, which we view as a hallucinatory phenomenon. Hallucinations have received a number of definitions, most of them referring to sensory experiences.[33] However, the concept of non-sensory hallucinations was forwarded at the end of the nineteenth century, and, more recently, Nielsen took FP as an example to stress that an “image” was not mandatory to consider an experience as a hallucination.[22] A FP shares with hallucinations the vividness of the sensation and a projection into the extracorporeal space, with precise spatial features in most cases. Moreover, in our study, patients with FP were more likely than patients without FP to have visual illusions and VH. Further evidence of a hallucinatory mechanism is the concomitant presence of unformed VH in about one-third of our patients, the sense of presence being “bound” to the

elementary VH. Interestingly, experiences following bereavement include FP of the deceased (the most common type) as well as visual or auditory hallucinations (reviewed in ref 32, p.67-68). Finally, in a factor analysis of psychotic symptoms of dementia with Lewy bodies, VH of persons and FP were included in the same factor.[12]

What could be the neural basis for FP? Studies of epileptic subjects show that FP may result from abnormal activation of specific cortical areas. FP, in most cases associated with fear, may occur in partial epileptic seizures originating in the temporal lobe on either side[ 13-17]. Moreover, electrical brain stimulation during presurgical assessment of patients with medically intractable partial epilepsy may elicit FP.[16, 34, 35] Arzy *et al.* found that stimulation of an area at the left temporo-parietal junction during preoperative assessment of a young woman with epilepsy induced an “illusory shadow person” which the patient felt very close and mimicked her body posture and position.[35] The authors suggested that the patient was experiencing a perception of her own body due to multisensory and/or sensorimotor disintegration. A similar experience was elicited by stimulation of the left temporo-parieto-occipital junction in another patient with temporal lobe seizures.[16] Interpretation of FP as an externally projected self is in line with previous descriptions of the FP as a “non-visual autoscopy”. [36] Brugger *et al.*, [19] in a review of FP after brain damage, emphasized the phenomenological similarities between heautoscopy (“*a special type of autoscopic hallucination involving, along with the experience of seeing oneself, the somaesthetic awareness of the presence of one’s double*”) and FP, such as a frequent feeling of familiarity or of close psychological affinity with the presence; a distinct and specific distance from the person’s body and the possible imitation of all body movements; and cases in which heautoscopy and FP are experienced in close temporal succession.

Could the FP in PD result from projection of the self into the extrapersonal space? Such a mechanism is unlikely for several reasons. First, in 44% of cases the presence was identified as that of a precise relative, and, when the presence was unidentified, the patients never reported a feeling of familiarity. Second, the FP occasionally started when the relative left the patient’s presence, indicating an external trigger. Third, although the presence was usually felt in the patient’s close vicinity, it was sometimes located in another room or outside the house. Fourth, in one case the FP was that of a dog, which is hardly consistent with an illusory self. Finally, FP in our PD patients was never associated with autoscopic hallucinations, and we are unaware of any reports of autoscopic phenomena in PD.

We therefore consider that FP in PD patients corresponds to the perception of a person distinct from oneself. This view is in line with that of Nielsen concerning FP associated with

sleep paralysis attacks,[22] and with that of Picard who reported on a patient with FP of several familiar persons during a simple focal epileptic seizure.[17] There is extensive evidence that selective cortical regions are active during the perception of biological forms and the perception of biological motion. Specific areas of the visual extrastriate cortex respond selectively to faces (e.g. the fusiform face area[37]) or to the rest of the human body[38], while other areas of the superior temporal sulcus region are activated by movements of the eyes, mouth, hands and body, and by static images of the face and body of implied motion.[39] However, it is unlikely that FP results primarily from activation of these areas. For example, abnormal activation of the fusiform face area is associated with hallucinatory perception of a face and not with a felt presence[40] FP could involve another area or network that is specifically activated when a person (or pet), but not an object, is present, independently of any perceptual clues to this presence. The frequent familiarity of the living being whose presence is felt, and the high prevalence of FP following bereavement, point to a connection between this putative area and both affective and autobiographical memory networks. FP can also be modulated by prior knowledge and perceptual expectation, as exemplified by the phenomenon of palinparousia. As a result, FP may be viewed as a “social” hallucination.

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### **Competing interests**

None

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**Table 1** Demographic and clinical characteristics of patients experiencing a feeling of presence (n=52)

Mean age, years (SD, range)	67.0 (8.8, 46-84)
Men, n (%)	33 (62)
Mean disease duration, years (SD, range)	11.5 (6.5, 1.5-28)
Mean Hoehn and Yahr stage (in “on” state)	2.7 (0.8, 1-4)
Predominant side of parkinsonism, n (%)	
Right	19 (36)
Left	28 (54)
None	5 (10)
Mean L-dopa equivalent daily dose, mg (SD, range)	959 (472, 0-2535)
Current use of psychoactive drugs, n (%)	36 (69)
Current use of clozapine, n (%)	4 (8)
Mean BDI-II depression score (SD, range)	21.1 (7.6, 4-38)
Mean MMP cognitive score (SD, range)	25.4 (4.0, 14-31)

**Table 2** Characteristics of presence hallucinations in the 52 patients

<b>Content<sup>a</sup></b>		<b>Repercussions for the patient</b>	
Unidentified	30 (58)	<b><i>Insight</i></b>	
Identified, living	11 (21)	Present	40 (77)
Identified, deceased < 1 year	2 (4)	Absent or partial	12 (23)
Identified, deceased > 1 year <sup>b</sup>	12 (23)	<b><i>Influence</i></b>	
		Yes	5 (10)
<b>Temporal characteristics</b>		<b><i>Checking for a real presence</i></b>	
<b><i>Predominant schedule</i></b>		Yes	41 (79)
Evening or night	17 (33)	<b><i>Emotional impact</i></b>	
Sleep onset or outset	3 (6)	Unpleasant	20 (38)
Other or none	32 (62)	Neutral	28 (54)
<b><i>Frequency</i></b>		Pleasant	4 (8)
≥ 1 /day	16 (31)	<b>Visual experience concomitant with SP</b>	
< 1 / day and ≥ 1 / week	25 (48)	<b><i>Seeing a "shadow"</i></b>	16 (31)
< 1 / week	11 (21)	<b><i>Using imagery terms to describe the experience</i></b>	6 (12)
<b><i>Duration</i></b>		<b>Associated psychotic symptoms<sup>d</sup></b>	
Seconds	41 (79)	<b><i>Minor phenomena</i></b>	
Minutes	9 (17)	Visual illusions	30 (58)
Hours	2 (4)	Passage hallucinations	15 (29)
<b><i>Link with fluctuations</i></b>		At least one type	35 (67)
Present in "off" state	5 (10)	<b><i>Hallucinations</i></b>	
<b>Spatial characteristics</b>		Complex visual	20 (38)
<b><i>Location of the "presence"</i></b>		Auditory	14 (27)
Behind	14 (27)	Tactile	14 (27)
To one side <sup>c</sup>	30 (58)	Olfactory	9 (17)
Other room	6 (12)	Gustatory	5 (10)
Other / unknown	2 (4)	At least one type	32 (62)
<b><i>Location of the patient</i></b>		<b><i>Delusions</i></b>	
Indoors	41 (79)	Present	7 (13)
Outdoors	3 (6)		
Indoors or outdoors	8 (15)		

Values are numbers of patients (%). a. Three patients felt two types of presence. b. In one case, the felt presence was that of a dog previously owned by the patient. c. Right side: 10 (19%); left side: 9 (17%); one or the other side (or uncertain): 11 (21%). d. Associated psychotic symptoms did not occur concomitantly with the sense of presence

**Table 3** Characteristics of consecutive outpatients with and without a feeling of presence

	<b>Patients with FP n=38</b>	<b>Patients without FP n=78</b>	<b><i>p</i></b>
Mean age, years (SD)	67.4 (9.2)	66.9 (10.3)	NS
Men, n (%)	26 (68)	49 (63)	NS
Mean disease duration, years (SD)	11.2 (5.9)	8.1 (5.7)	0.006
Mean Hoehn and Yahr stage in “on” state (SD)	2.5 (0.8)	1.9 (0.8)	< 0.001
Predominant side of parkinsonism, n (%)			
Right	15 (39)	37 (48)	
Left	19 (50)	35 (45)	NS
None	4 (11)	5 (7)	
Mean L-dopa equivalent daily dose, mg (SD)	892 (389)	683 (431)	0.019
Current use of dopaminergic agonists <sup>a</sup> , n (%)	23 (61)	51 (65)	NS
Current use of amantadine, n (%)	10 (26)	8 (10)	0.031
Current use of anticholinergics, n (%)	7 (18)	6 (8)	NS
Current use of psychoactive drugs, n (%)	23 (61)	23 (30)	0.002
Associated psychotic symptoms, n (%)			
Visual illusions	21 (55)	7 (9)	<0.001
Visual hallucinations	14 (37)	5 (6)	<0.001
Non-visual hallucinations	17 (45)	21 (27)	NS

a. Dopaminergic agonists were in most cases non ergot derivatives (piribedil, pramipexole, or ropinirole) and in a few instances ergot derivatives (bromocriptine, lisuride, or pergolide),

**Table 4** Factors predictive of feeling of presence (multivariate logistic regression)

	<b>Odds ratio (95% confidence interval)</b>	<b><i>p</i></b>
Levodopa-equivalent daily dose (>750 mg)	1.7 (1.1-2.8)	0.029
Visual illusions	4.6 (1.6-12.8)	0.004
Visual hallucinations	4.5 (1.2-16.4)	0.023