A questionnaire on sleep and mental disorders in Parkinson’s disease (QSMDPD): development and application of a new screening tool

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Summary

Psychiatric, cognitive and sleep disorders are the most frequent and disabling non-motor complications of Parkinson’s disease (PD).

To improve the description of sleep and mental disorders in PD patients, we set out to develop a simple and reliable data collection tool (questionnaire) for the screening of large samples of PD patients.

The first draft of the questionnaire was administered to a consecutive series of 120 PD patients from the outpatient department of our unit, who were instructed to fill it in with the help of their caregivers. Subsequent drafts of the questionnaire were evaluated together with the patients and their caregivers, until a final, satisfactory version was obtained.

This final version was named the Questionnaire on Sleep and Mental Disorders in PD (QSMDPD). This questionnaire – we used the Italian version, named Questionario sui Disturbi del Sonno e Mentali nella Malattia di Parkinson, QDSMMP – consists of 119 questions with multiple-choice answers.

The QSMDPD was mailed or handed to 400 PD patients followed at our unit’s outpatient department. Three hundred and twenty (80%) were returned to us. A review of these completed questionnaires, conducted by a neurologist together with the patients, showed 90% of them (289) to be complete and to provide reliable data. This high compliance suggests that the QSMDPD is a promising tool for collecting data on sleep and mental disorders in large samples of PD patients. A short version will be administered as a follow-up tool.

KEY WORDS: hallucinations, Parkinson’s disease, REM behaviour disorder, sleep disorders.

Introduction

Psychiatric, cognitive and sleep disorders are the most frequent and disabling non-motor complications of Parkinson’s disease (PD). Indeed, around 60% of PD patients report sleep disorders, which include frequent awakenings, daytime sleepiness, altered dream phenomena, and REM behaviour disorder (RBD).

Some authors have suggested that these phenomena could precede the onset of motor symptoms (1,2). A close relationship between the occurrence of visual hallucinations and both NREM and REM sleep in PD has been reported (3,4), reinforcing the hypothesis that the mechanisms underlying dream imagery are likely to play a role in the genesis of visual hallucinations in PD (4).

Another important aspect of hallucinations in PD is that they have often been seen to coincide with the onset of cognitive impairment (5).

The aim of this study was to estimate the occurrence of REM sleep disorders (in particular RBD), daytime sleepiness and mental disorders (hallucinations, delusions and confusional states) in a large sample of PD patients, collecting data that, as well as improving the description of these disorders, might also allow us to establish their relationship with the natural history of the disease and to verify the hypothesis of a possible correlation between the presence of RBD and the onset of mental disorders.

To these ends, we developed a specific questionnaire. The primary aim of this paper is to present the final version of this questionnaire and to demonstrate its potential usefulness as a tool for collecting clinical data and describing mental and sleep disorders in large samples of PD patients.

The data gathered will be submitted to descriptive statistical analysis and analysis of correlations.

Materials and methods

For the sleep disorders part of our questionnaire (Part I), we took as a starting point the “Sleep Disorders Questionnaire” of Douglass et al. (6), but also devised new ad hoc items. The first draft of this new question-
naire was administered to a series of 120 PD patients consecutively attending our unit’s outpatient department, who were instructed to fill it in with the help of their caregivers. Subsequent drafts were evaluated together with the patients and their caregivers, until a consistent and satisfactory version (the final version) was obtained.

The final version was mailed or handed to PD patients followed at our unit’s outpatient department. They were asked to return it, filled in, at their next clinical check up, when it would be checked by a clinician specialising in sleep medicine. Part II of the questionnaire, reserved for patients reporting hallucinations, behavioural disorders and confusional states, had to be filled in by the neurologist.

The established period for data collection was 1 year, from January to December 2002. Patients were instructed, when answering the questions, to refer to the six-month period immediately prior to compilation of the questionnaire.

The contents of the final version

The final version was named the Questionnaire on Sleep and Mental Disorders in PD (QSMDPD) – we administered our patients the corresponding Italian version, entitled: Questionario sui Disturbi del Sonno e Mentali nella Malattia di Parkinson, ODSMMP – and it consisted of 119 questions with multiple-choice answers, divided into two parts. Part I covered personal data, and included questions about life habits, sleep characteristics and disorders, and daily sleepiness (Enclosure A). Patients were also sent the validated Italian version (7) of the Epworth Sleepiness Scale (8) (Enclosure B) for the quantification of subjective diurnal sleepiness. Part II of the questionnaire, which was to be compiled by the neurologist, included questions about hallucinations (Enclosure C), delusions and behavioural disorders (Enclosure D), episodes of confusional state (Enclosure E). The questionnaire was preceded by the Happiness Measure (9), for the assessment of mood, and by a section for the collection of clinical data, such as age at PD onset, years of therapy, Hoehn and Yahr stage, Unified Parkinson’s Disease Rating Scale III (UPDRS III) score, Schwab and England score, and Mini Mental State Examination score, on an ad hoc datasheet. The complete QSMD-PD is here presented in the English version (see Appendix).

Results

In the course of one-year data collection period, 400 questionnaires were distributed, of which 320 have been returned completed by patients. A review of these completed questionnaires, conducted by a neurologist together with the patients, showed 90% of them (289) to be complete and to provide reliable data.

Questions about life and sleep habits, even very detailed ones, were always well understood and correctly answered without help. Conversely, the answers to questions about sleep disorders, particularly those referring to their temporary relationships with PD, were less complete in the 390 questionnaires returned to us, and we found that patients needed more stimulation and guidance in considering and answering them during the semi-structured interview based on the questionnaire. Many patients elaborated on the simple multiple-choice answers, also supplying written descriptions of their visions or dreams.

The sample data was analysed and submitted to statistical analysis, as shown in Table I (in which errors are expressed as standard deviations). A total of 191 patients were in an advanced stage of PD at the time of filling in the questionnaire. Data relating to dopaminergic therapy and other pharmacological treatments were collected by the neurologist; and the relative descriptive

Table I - Demographic and clinical characteristics of the sample.

| Total sample= 289 subjects. Males=155; mean age: 67.70±8.91 yrs; females=134; mean age: 69.00±8.59 yrs |
|---|---|---|
| Age at PD onset | All patients: 59.76±10.21 yrs | Advanced disease (191 patients): 63.22±9.36 yrs |
| (mean) | | |
| H&Y | All patients: 2.5 | Advanced disease (191 patients): 3 |
| (median) | | |
| UPDRS III | All patients: 24.41±12.35 | Advanced disease (191 patients): 41.08±15.23 |
| (mean) | | |
| Schwab & England | 78.87±17.05% | |
| MMSE | 26.20±3.54 | |
| (mean) | (<23=13.19%) | |
| ESS | 6.75±5.31 | |
| (mean) | (>10=26.64%) | |
| HM | 45.92±20.38 | |
| (mean) | (>40=63.86%) | |

Abbreviations: PD=Parkinson’s disease; H&Y=Hoehn & Yahr stage; UPDRS=Unified Parkinson’s disease rating scale; MMSE=Mini Mental State Examination score; ESS=Epworth Sleepiness Scale; HM=Happiness Measure.
statistics are given in Table II (errors expressed as standard deviations).
RBD was reported by 191 subjects: in 114 of them it was moderate, accompanied by sleep-talking with or without vivid dreams, and without sleep-related violence; 77 had severe RBD with sleep-related violent behaviour with or without sleep-talking and/or vivid dreams.
Ninety-two patients reported mental disorders, such as hallucinations, delusions, and/or confusional state.

Table II - Dopaminergic therapies.

<table>
<thead>
<tr>
<th>Treatment</th>
<th>Number of Patients</th>
<th>Percentage</th>
<th>Mean Equivalent Dose (mg)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Levodopa and dopamine agonist</td>
<td>200</td>
<td>69.2%</td>
<td>941.12±316.30</td>
</tr>
<tr>
<td>Levodopa (monotherapy)</td>
<td>73</td>
<td>25.3%</td>
<td>648.21±222.81</td>
</tr>
<tr>
<td>Dopamine agonist (monotherapy)</td>
<td>16</td>
<td>5.5%</td>
<td>236.25±140.24</td>
</tr>
<tr>
<td>Entacapone</td>
<td>47</td>
<td>16.3%</td>
<td></td>
</tr>
</tbody>
</table>

Other pharmacological treatments

<table>
<thead>
<tr>
<th>Treatment</th>
<th>Number of Patients</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Amantadine</td>
<td>34</td>
<td>11.8%</td>
</tr>
<tr>
<td>Anticholinergics</td>
<td>11</td>
<td>3.8%</td>
</tr>
</tbody>
</table>

Discussion

The significant number of the mailed questionnaires subsequently returned to the neurologist confirms a good level of compliance, and 90% of these returned questionnaires were judged to be complete and suitable for analysis. The high correspondence between answers and clinical history indicated that the questions developed were clear and comprehensible.

Preliminary descriptive statistics show that the questionnaire, in its final version, allows the collection of data that are useful both for obtaining a detailed description of the sample studied and for investigating, in a future study, correlations between variables.

In conclusion, the QSMDPD emerged as a promising tool for investigating and describing sleep and mental disorders in large samples of patients with PD. A short version of the QSMDPD has been formulated, and is currently being administered – this phase of our study began in January 2004 – to the 289 patients who completed the first version, to follow up both sleep and mental disorders already reported and new-onset ones.

References

APPENDIX

QUESTIONNAIRE ON SLEEP AND MENTAL DISORDERS
IN PARKINSON’S DISEASE
(QSMDPD 2001 - PAVIA)

I) Part I of this questionnaire (made up of enclosures A and B) evaluates sleep disorders in people with Parkinson’s disease. Fill it in with the help of a family member or a friend. All you have to do is put a cross next to your answer. Give only one answer per question, except for questions in which the possibility of giving more than one answer is indicated.

E.g.: Why do you wake up? (you can give more than one answer)
1........because I'm not able to turn over in bed
2........because I have painful cramp in my legs or dystonia
3........because I need to urinate
4..........I wake naturally, for no apparent reason and not because of any discomfort
5........because of feelings of agitation and/or anxiety
6.........because I am trembling
9........other

II) Part II (enclosures C D E ) must be filled in only if you have had hallucinations in the past six months. To compile this part, you will need the help of your neurologist. You are also asked to fill in the “Happiness Measure”.
Thank you for your collaboration.

CONSENT TO THETREATMENT OF PERSONAL DATA

In response to the request for consent to the treatment of personal data, and having read the relevant information sheet, taking note in particular of rights attributed under the terms of art. 13 of Law 675/1996,
the undersigned ................................................................. (write in capital letters)
born in ................................................................. on .........................
resident at .................................................................................................................................
authorises the transmission of his/her personal data for scientific and statistical purposes, and for the promotion of health, on condition that these data have first been rendered anonymous and not traceable, either directly or indirectly, to the individual in question, in conformity with the provisions laid down in law 675/96.
In faith
Place and date .................................................................

Legible signature

DATA COLLECTION SHEET
(to be filled in by your neurologist)

Date of compilation .................................................................
Name and surname .................................................................
Age........................ Date of birth ..........................
Telephone No. .................................................................

Clinical Data
Age at onset of Parkinson’s disease .................................................................
Age at onset of advanced stage of the disease (on-off, dyskinesias) .................................................................
Years of levodopa therapy .................................................................
Years of treatment with dopamine agonists .................................................................
Hoehn and Yahr stage ................................................................. in “on” ............... in “off”
UPDRS III ................................................................. in “on” ............... in “off”
Schwab and England .................................................................
Mini Mental State .................................................................
**Happiness Measure**

This scale is designed to “measure” mood, so to tell us about how happy or unhappy you feel. Answer the following question putting a cross next to the answer that best reflects your mood in the last 6 months.

*How happy do you usually feel (on average)*?

10........Extremely happy (I feel fantastic, and am in a joyful, almost ecstatic mood)
9........Very happy (I feel great)
8........Quite happy (I feel good, my mood is upbeat)
7........Averagely happy (I’m OK, and on good form)
6........Slightly happy (I feel just a bit happier than neutral)
5........Neutral (neither particularly happy or unhappy)
4........Slightly unhappy (I feel just a bit unhappier than neutral)
3........Averagely unhappy (I’m a little depressed)
2........Rather unhappy (I’m rather down, and in a bad mood)
1........Very unhappy (I feel depressed, low-spirited)
0........Extremely unhappy (I’m deeply depressed, and completely down)

Now consider your emotions more carefully. For what proportion of the past six months (in percentage terms) were you happy, on average? And for what proportion of the past six months (in percentage terms) were you unhappy? And for what proportion of the past six months (in percentage terms) were you neither unhappy or happy (indifferent)?

*Write your answers below and check that your scores make a total of 100%*

**On average**

The proportion of time I have felt happy .......................................%  
The proportion of time I have felt unhappy ...................................%  
The proportion of time I have felt indifferent ................................%  
Total ................................ 100%

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Before starting to fill in the questionnaire, please write down all the details of your current therapy.

Write the names of the drugs you are taking.

If the dose is written on the box remember to write it down (for example Sinemet 25/100).

Write how many tablets you take per day, too.

Remember to mention all the drugs you are taking!

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**Part I**

**Enclosure A**

**Personal data**

Date of compilation ...................................................
Name and surname ..........................................................
Address and telephone no. ...............................................

1) Age .....................
2) Sex ................................. M ............. F ............
3) Weight (kg) .....................
4) Height (cm) .................

5) Birthplace:
   1........Pavia
   2........an Italian province other than Pavia
   3........an Italian region other than Lombardy
   4........another part of northern Italy
   5........central Italy
   6........southern Italy (including the islands)
   7........outside Italy

6) Where do you live?
   1........Pavia
   2........an Italian province other than Pavia
   3........an Italian region other than Lombardy
   4........another part of northern Italy
   5........central Italy
   6........southern Italy (including the islands)

7) You live in:
   1........a major regional town/city
   2........a major provincial town/city
   3........a smaller town
   4........the country

8) Schooling:
   1........illiterate, did not complete primary school
   2........primary school leaving certificate
   3........middle school leaving certificate
   4........professional diploma (triennial courses)
   5........upper school leaving certificate
   6........degree certificate

9) Occupational status:
   1........Retired
   2........Retired due to infirmity
   3........Employee
   4........Self-employed
   5........Housewife
   6........Unemployed
   7........Other

10) Do you drive?
    9........no driving licence
    0........never
    1........sometimes
    2........often (almost every day)
    3........always (every day)

Data on daily habits

11) Do you drink coffee during the day?
    0........I have never drunk coffee
    1........I don't drink coffee any more (how long? .................)
    2........Yes, I drink coffee (how many cups a day? ..............)

12) Do you drink spirits?
    0........I have never drunk spirits
    1........I don't drink spirits any more (how long? ..............)
    2........I sometimes drink spirits
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3.……I often drink spirits (3-4 times a week)
4.……I drink spirits every day

13) How many cigarettes do you smoke a day?
0.……I have never smoked
1.……I don’t smoke any more (how long?……………)
2.……I smoke up to 10 cigarettes a day
3.……I smoke between 11 and 20 cigarettes a day
4.……I smoke between 21 and 30 cigarettes a day
5.……I smoke between 31 and 40 cigarettes a day
6.……I smoke more than 40 cigarettes a day

14) Do you nap after dinner and before going to bed, while watching TV or while sitting in a chair reading?
0.……never
1.……sometimes
2.……often
3.……always

15) Do you take specific drugs to help you sleep?
0.……never
1.……sometimes
2.……often
3.……always

16) How long have you been taking drugs to help you sleep?
1.……for 1 month
2.……for more 1 month but less than 3 months
3.……for more 3 months but less than 6 months
4.……for between 6 months and 1 year
5.……for over 1 year (specify how long ……………..)

What drugs do you take? ……………………………………………

Sleep data

17) Do you usually sleep with somebody else in the bedroom?
1.……no
2.……yes

18) What time do you usually go to bed ?
1.……before 9 p.m.
2.……between 9 p.m. and 10 p.m.
3.……between 10 p.m. and 11 p.m.
4.……between 11 p.m. and 12 p.m.
5.……after 12 p.m.

19) How long does it take you to fall asleep?
1.……less than 30 minutes
2.……between 30 and 60 minutes
3.……more than 60 minutes

20) Do you usually have difficulty falling asleep ?
1.……no
2.……yes

If your answer to question 20 is “1……no”, go directly to question22

21) If you have difficulty falling asleep, is it due to your Parkinson’s disease?
(you can give more than one answer)
1.……no
2.……yes, because I have difficulty turning over in bed
3.……yes, because I tremble
4.……yes, because I am in pain
5.……other (specify ……………………………………..)
22) Do you usually wake up during the night?
   0........never
   1........once
   2........twice
   3........more than twice

   If your answer to question 22 is "0......never", go directly to question 27

23) Why do you wake up? (you can give more than one answer)
   1.......because I’m not able to turn over in bed
   2.......because I have painful cramp in my legs or dystonia
   3.......because I need to urinate
   4.......I wake naturally, for no apparent reason and not because of any discomfort
   5.......because of feelings of agitation and/or anxiety
   6.......because I am trembling
   7.......because I have pains in my joints
   8.......because I’m having difficulty breathing
   9.......other (specify .................................................................)

24) If you usually wake up in the night, what do you generally do? (you can give more than one answer)
   1.......I stay in bed without doing anything, hoping to fall asleep again
   2.......I switch on the light and begin reading
   3.......I watch TV
   4.......I get up and go to eat and/or drink something
   5.......I get up to go to the bathroom
   6.......other (specify.................................................................)

25) Do you usually have difficulty falling asleep again?
   0........never
   1.......sometimes
   2.......often
   3.......always

26) How long does it take to you to fall asleep again?
   1.......less than 30 minutes
   2.......between 30 and 60 minutes
   3.......more than 60 minutes

27) How are you when you wake up in the morning, as a rule?
   1.......rested
   2.......not rested

28) Has anyone ever told you that you hold your breath while you are sleeping?
   0........never
   1.......sometimes
   2.......often
   3.......always
   9.......I don’t know

29) Have you ever been woken up by a sensation of gasping for breath?
   0........never
   1.......sometimes
   2.......often
   3.......always
   9.......I don’t know

30) Do you snore at night?
   0........never
   1.......sometimes
   2.......often
   3.......always
   9.......I don’t know
31) Do you wake up too early in the morning (i.e., earlier than you would want to, or need to)?
   0......never
   1......sometimes
   2......often
   3......always

32) How many hours do you sleep each night on average?
   1......less than 6 hours
   2......between 6 and 7 hours
   3......between 7 and 8 hours
   4......between 8 and 9 hours
   5......more than 9 hours

33) At what time do you usually wake up in the morning?
   1......before 6 a.m.
   2......between 6 a.m. and 7 a.m.
   3......between 7 a.m. and 8 a.m.
   4......between 8 a.m. and 9 a.m.
   5......between 9 a.m. and 10 a.m.
   6......after 10 a.m.

34) Do you find it hard to wake up?
   0......never
   1......sometimes
   2......often
   3......always

35) How long, after awakening, does it take you to feel wide awake and lucid?
   1......between 0 and 10 minutes
   2......between 11 and 20 minutes
   3......between 21 and 40 minutes
   4......more than 40 minutes

36) When, in daylight hours, do you feel most awake and active?
   1......in the course of the morning
   2......after lunch
   3......during the afternoon
   4......after dinner
   5......there is no particular time at which I feel most awake and active

37) Do you think you usually get the right number of hours' sleep?
   1......no
   2......yes

38) Do you dream at night?
   0......never
   1......sometimes
   2......often
   3......always

39) If you dream, are your dreams vivid and almost real?
   1......my dreams are never vivid
   2......sometimes
   3......often
   4......always

40) Do you ever have nightmares?
   0......never
   1......sometimes
   2......often
   3......always

If your answer to question 38 is "0......never", go directly to question 43
41) If you have had nightmares, can you remember what sensations/emotions you felt?
1……..no
2……..fear, terror
3……..anger, violence
4……..other (specify ……………………………………………………………………)

42) How often do you have vivid dreams or nightmares (refer to the past 6 months)?
0……..I haven’t had vivid dreams or nightmares in the past 6 months
1……..sometimes (less than 1-2 times a month)
2……..often (1-2 times a week)
3……..almost every day

43) How often do you talk in your sleep (refer to the past 6 months)?
0……..I never talk in my sleep
1……..sometimes (less than 1-2 times a month)
2……..often (1-2 times a week)
3……..almost every day

44) How often do you scream in your sleep (refer to the past 6 months)?
0……..I never scream in my sleep
1……..sometimes (less than 1-2 times a month)
2……..often (1-2 times a week)
3……..almost every day
9……..I don’t know

45) How often do you have episodes of restless sleep with violent behaviour towards the person sleeping near you, without insight (refer to the past 6 months)?
0……..I never have episodes of restless sleep with violent behaviour
1……..sometimes (less than 1-2 times a month)
2……..often (1-2 times a week)
3……..almost every day
9……..I don’t know

46) If you talk in your sleep or if you have vivid dreams or episodes of restlessness and violent behaviour during sleep, do you think these episodes began when you started taking any of the following drugs?
1……..no
2……..Madopar
3……..Sinemet
4……..Comtan
5……..Nopar
6……..Mirapexin
7……..Requip
8……..other (specify the name of drug ……………………………..)

47) If you talk in your sleep or if you have vivid dreams or episodes of restlessness and violent behaviour during sleep, do you think these disorders increased when you started taking any of the following drugs?
1……..no
2……..Madopar
3……..Sinemet
4……..Comtan
5……..Nopar
6……..Mirapexin
7……..Requip
8……..other (specify the name of drug ……………………………..)

48) Did you talk in your sleep before the onset of your Parkinson’s disease?
1……..no
2……..yes

49) For how long before the onset of your Parkinson’s disease had you been talking in your sleep?
1……..for months (specify how many months……………..)
2……..for years (specify how many years……………..)
50) How often did you talk in your sleep before the onset of your Parkinson’s disease?
1........not often (less than 1-2 times a month)
2........often (1-2 a week)
3........almost every day

51) Did you have vivid dreams before the onset of your Parkinson’s disease?
1........no
2........yes

52) For how long before the onset of your Parkinson’s disease had you been having vivid dreams?
1........for months (specify how many months ……………..)
2........for years (specify how many years ……………..)

53) How often did you experience vivid dreams before the onset of your Parkinson’s disease?
0........never
1........sometimes (less than 1-2 times a month)
2........often (1-2 times a week)
3........almost every day

54) Did you have episodes of restless sleep with violent behaviour before the onset of your Parkinson’s disease?
1........no
2........yes

55) How long before the onset of your Parkinson’s disease had you been having episodes of restless sleep with violent behaviour?
1........months (specify how many months ……………..)
2........years (specify how many years ……………..)

56) How often did you have episodes of restless sleep with violent behaviour before the onset of your Parkinson’s disease?
0........never
1........sometimes (less than 1-2 times a month)
2........often (1-2 times a week)
3........almost every day

57) Has there been any change in these episodes since the onset of your Parkinson’s disease?
1........they have stopped occurring
2........no, there has been no change
3........yes, they have increased

58) Have you begun to talk in your sleep or to have vivid dreams or restless and sleep with violent behaviour since the onset of your Parkinson’s disease?
1........no
2........yes

If your answer to question 58 is “1......no”, go directly to question 62

59) How long after the onset of your Parkinson’s disease did you begin talking in your sleep?
1........months (specify how many months……………..)
2........years (specify how many years……………..)

60) How long after the onset of your Parkinson’s disease did you begin having vivid dreams?
1........months (specify how many months……………..)
2........years (specify how many years……………..)

61) How long after the onset of your Parkinson’s disease did you begin having episodes of restless sleep with violent behaviour?
1........months (specify how many months ……………..)
2........years (specify how many years ……………..)

62) Has anybody ever told you that, in childhood:
1........you used to talk in your sleep
2........you used to wake up suddenly screaming or crying, showing an intense manifestation of fear
3........you used to have episodes of sleep-walking
4........none of these

63) Do you ever grind your teeth during sleep?
0........never
1........sometimes
2........often
3........always
9........I don’t know
Daily sleepiness data

64) Do you ever experience sleepiness during the daytime?
   0........never
   1........sometimes
   2........often
   3........always

If your answer to the above question is 1, 2, or 3, please answer the questions in Enclosure B, as well as continuing with this questionnaire. If, on the other hand, you answered “0…..never”, then you have come to the end of Part I of the questionnaire. Thank you.

65) How long have you been experiencing sleepiness during the daytime?
   1........3 months
   2........6 months
   3........one year
   4........years (specify how many years ………………….)

66) When do you experience it ?
   1........in the course of the morning
   2........after lunch
   3........during the afternoon
   4........after dinner
   5........at any time

67) Do you take a short nap after lunch?
   0........never
   1........sometimes
   2........often
   3........always

68) Does the sleepiness interfere with your daily activities?
   0........never
   1........sometimes
   2........often
   3........always

69) Have you ever had a “sleep attack” (an episode of sudden onset of sleep)?
   0........never
   1........sometimes
   2........often
   3........always

70) Has the sleepiness interfered with your driving?
   0........no, not at all
   1........yes, risk of accidents
   2........yes, car accident (include going off the road)
   9........no, I don’t drive

71) Did the sleepiness begin following modification of your therapeutic regimen ?
   1........no
   2........yes

72) If so, which of these drugs was the cause?
   When I started:
   1........Madopar
   2........Sinemet
   3........Comtan
   4........Mirapexin
   5........Nopar
   6........Requip
   7........Leponex
   8........Seroquel
   9........other (specify the drug ………………….)
   10........I don’t know
Enclosure B

_Epworth sleepiness scale_

How likely are you to doze off or fall asleep in the following situations, in contrast to feeling just tired? This refers to your usual way of life in recent times. Even if you have not done some of these things recently try to work out how they would have affected you. Use the following scale to choose the most appropriate number for each situation.

0 = would never doze
1 = slight chance of dozing
2 = moderate chance of dozing
3 = high chance of dozing

SITUATIONS (write the score at side):

Sitting and reading ...................................................................................................................................................................................
Watching TV ............................................................................................................................................................................................
Sitting inactive in a public place (e.g., a theatre or a meeting) .................................................................................................................
As a passenger in a car for an hour without a break ................................................................................................................................
Lying down to rest in the afternoon, when circumstances permit ............................................................................................................
Sitting and talking to someone .................................................................................................................................................................
Sitting quietly after lunch without alcohol ..................................................................................................................................................
In a car, while stopped for a few minutes in the traffic ............................................................................................................................

**PART II**

Enclosure C

_Data on hallucinations_

73) Have you ever had an altered perception of objects (e.g., strange forms, colours, a leaf that seems to turn into a face, etc.) or seen or heard something no one else could see or hear?
   1......no
   2......yes

74) How long have you been having hallucinations?
   1......days (specify how many ............)
   2......months (specify how many ............)
   3......years (specify how many ............)

75) When have you experienced hallucinations? (you can give more than one answer)
   1......at night
   2......in the day
   3......in the evening
   4......both in the day and at night

76) At what point of the night or evening do you have hallucinations? (you can give more than one answer)
   1......as I am falling asleep
   2......as I am waking up in the middle of the night
   3......while I’m awake

77) If you switch on the light do the hallucinations disappear ?
   1......no
   2......yes

78) At what time do you have hallucinations?
   1......5-9 p.m.
   2......9-12 p.m.
   3......12 p.m.-4 a.m.
   4......4-7 a.m.
   5......it varies

If your answer to question 75 is “2......in the day”, go directly to question 81

If your answer to question 73 is “1......no” don’t go on!

Go directly to enclosure D. Thank you
79) What do you do after these episodes?
   1. I fall asleep again
   2. I stay awake

80) If you stay awake, do you feel excited?
   0. I don’t stay awake
   1. no
   2. yes

81) When do you have hallucinations during the day? (you can give more than one answer)
   1. on falling asleep for a short nap
   2. on awakening from a nap
   3. after a short nap, when I’m still rather confused
   4. at any time of day, when I’m wide awake

82) Is there a relation with degree of lighting?
   1. no
   2. yes

83) What kind of hallucinations do you usually have, either in the day or at night? (you can give more than one answer)
   1. visual
   2. auditory
   3. tactile
   4. olfactory
   5. gustatory

84) If they are visual what, do you see? (you can give more than one answer)
   1. shadows passing near me (specify whether they resemble something real, e.g., people or animals)
   2. objects that change shape, or are strange colours or sizes
   3. small motionless animals
   4. small animals on the move
   5. small or medium-size animals, which are motionless
   6. small or medium-size animals, which are on move
   7. people, men, women and children, at the side of the bed or seated, still and silent
   8. people, men, women and children, moving
   9. complex and articulated scenes, like scenes from a film

85) If they are visual, are they...
   1. black and white?
   2. coloured?

86) If they are auditory, what do you hear?
   1. people’s voices (give more details on a separate sheet)
   2. music (give more details on a separate sheet)
   3. other (give more details on a separate sheet)

87) When you have hallucinations, are you convinced that what you are experiencing is real?
   1. no
   2. yes

88) When you have hallucinations, do you feel afraid and excited?
   1. no
   2. yes
   3. yes, I ask for help and call out for somebody
   4. yes, I scream and become violent

89) With what frequency do they occur?
   1. occasional (1-2 times a week)
   2. medium (1-2 times a day)
   3. high (more times a day)
90) How long do they last?
1........seconds (specify how many ..................)
2........minutes (specify how many ..................)
3........hours (specify how many .................)

91) If the hallucinations started following modification of your therapeutic regimen, which of these drugs was the cause?
1.......they did not start following modification of therapy
2........Madopar
3........Sinemet
4........Comtan
5........Mirapexin
6........Nopar
7.......Requip
8........other (specify the drug..................)

92) Are you taking drugs for hallucinations at the present time?
1.......no
2.......yes

93) If your answer to question 92 is yes, specify the kind of drug and the dose.
1.......Leponex    a) dose ........
2.......Seroquel    b) dose ........
3.......Zyprexa    c) dose ........
4.......other      d) dose ........

Enclosure D

Data on delusions and behavioural disorders

94) Have you experienced delusions in the past 6 months?
1.......no
2.......yes

95) How long have you been having them?
1.......days (specify how many ............)
2.......months (specify how many ............)
3.......years (specify how many ............)

96) What kind of delusions are they?
1.......delusions of guilt or persecution
2.......erotomaniac delusions
3.......deviated sexuality
4.......jealousy
5.......other

Please give one or more examples on a separate sheet. Thank you.

97) Are the delusions associated with excitement and states of emotional tension?
1.......no
2.......yes

98) Are the delusions associated with violent behaviour towards family or other people?
1.......no
2.......yes

99) With what frequency do these episodes occur?
1.......occasional (1-2 times a week)
2.......medium (1-2 times a day)
3.......high (more times a day)

100) How long do they last?
1.......seconds (specify how many ............)
2.......minutes (specify how many ............)

If your answer to question 94 is "1......no", don't go on! Go on to enclosure E. Thank you.
3. _______ hours (specify how many …………………..)

101) Did you have to be sedated urgently when you had these episodes?
1. _______ no
2. _______ yes

102) If these delusions started following modification of your therapeutic regimen, which of the following drugs was the cause?
1. _______ they did not start following modification of therapy
2. _______ Madopar
3. _______ Sinemet
4. _______ Comtan
5. _______ Mirapexin
6. _______ Nopar
7. _______ Requip
8. _______ other (specify the drug…………………..)

103) Are you currently taking drugs for delusions?
1. _______ no
2. _______ yes

104) If you answered yes to question 103 write the kind of drug and its dose.
1. _______ Leponex a) dose …………..
2. _______ Seroquel b) dose …………..
3. _______ Zyprexa c) dose …………..
4. _______ other d) dose …………..

Enclosure E

Data on episodes of confusional state

105) Have you had episodes of confusional state in the past 6 months?
1. _______ no
2. _______ yes

106) How long have you been having them?
1. _______ days (specify how many ………………)
2. _______ months (specify how many ………………)
3. _______ years (specify how many ………………)

107) Are these episodes of confusional state associated with excitement or states of emotional tension?
1. _______ no
2. _______ yes

108) Are they associated with violent behaviour or failure to recognise people?
1. _______ no
2. _______ yes

109) When do they occur?
1. _______ at night
2. _______ during the day (daylight hours)
3. _______ at any time of the day or night

110) At what point during the night do they occur?
1. _______ as I am falling asleep
2. _______ as I am waking up in the middle of the night
3. _______ while I am awake

111) At what time do they most frequently occur?
1. _______ between 9 and 12 p.m.
2. _______ between 12 p.m. and 4 a.m.
3. _______ between 4 and 7 a.m.
4. _______ it varies

112) When exactly do you experience episodes of mental derangement during daylight? (you can give more than one answer)
1. as I am falling asleep
2. as I am waking up from a short nap
3. at any time of the day

113) With what frequency do these episodes occur?
1. occasional (1-2 times a week)
2. medium (1-2 times a day)
3. high (more times a day)

114) How long do they last?
1. seconds (specify how many)
2. minutes (specify how many)
3. hours (specify how many)

115) Are they associated with delusions?
1. no
2. yes
3. sometimes

116) Are they associated with hallucinations?
1. no
2. yes
3. sometimes

117) If the episodes of confusional state began following modification of your therapeutic regimen, which of the following drugs was the cause?
When I started:
1. Madopar
2. Sinemet
3. Comtan
4. Mirapexin
5. Nopar
6. Requip
7. other (specify the drug)

118) Are you presently taking drugs for confusional state?
1. no
2. yes

119) If you answered yes to question 118, specify the kind of drug and the dose.
1. Leponex a) dose
2. Seroquel b) dose
3. Zyprexa c) dose
4. other d) dose