Characterization of Burning Mouth Syndrome in Patients with Parkinson's Disease

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Aims: To determine the prevalence and characteristics of burning mouth syndrome (BMS) in a Parkinson's disease (PD) population through a self-administered, custom-made survey. **Methods:** A total of 218 surveys were collected during regular outpatient visits at two Movement Disorders Clinics in Montreal (Canada) and Toulouse (France) to gather information about pain experience, PD-related symptoms, and oral and general health. A neurologist confirmed the diagnosis of PD, drug treatment, Hoehn-Yahr stage, and Schwab & England Activity of Daily Living score. Data between groups were compared using the independent samples Mann-Whitney U test and two-sided exact Fisher test. **Results:** Data from 203 surveys were analyzed. BMS was reported by eight subjects (seven females and one male), resulting in a prevalence of 4.0% (95% confidence interval [CI] = 2.1–7.8). Five participants with chronic nonburning oral pain were excluded. PD severity and levodopa equivalent daily dose did not differ between non-BMS and BMS participants. Mean poor oral health index was higher in BMS compared to non-BMS subjects (49.0 vs 32.2 points, $P < .05$). BMS manifested after PD onset in seven patients, did not occur on a daily basis in four, and always coexisted with restless legs syndrome. **Conclusion:** This survey yielded a low prevalence of BMS in PD patients, indicating no strong link between the two conditions. An augmenting effect such as that resulting from drug treatment in restless legs syndrome or sensory neuropathy cannot be excluded.
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Keywords: *burning mouth syndrome, oral pain, Parkinson's disease*

The majority of patients living with Parkinson's disease (PD) experience chronic pain, whether the pain is related to PD or not.[1] Different classification schemes for diagnosing pain have been proposed; for instance, to distinguish dystonic from nondystonic pain.[2,3] Convincing evidence suggests that pain perception is altered in PD, with the demonstration of a lowered pain threshold[4] and activation of central nociceptive pathways[5] as examined by positron emission tomography (PET) in the off-drug condition and normalized following levodopa administration. Body localization has focused on the neck, shoulder, back, and extremities, with little data regarding the orofacial area.

Among the sources of chronic orofacial pain, stomatodynia, or burning mouth syndrome (BMS), is a condition typically described as a chronic painful burning sensation without any clinical alterations in the oral mucosa, present continuously for at least 4 to 6 months. The pain primarily involves the tongue but may extend to soft and hard tissues of the mouth.[6] BMS is classified as secondary when local, nutritional, or systemic factors are identified. In the absence of any identifiable cause, BMS is classified as primary or idiopathic. Depending on the underlying cause, the pain intensity may increase throughout the day (type 1), be continuous (type 2), or be intermittent (type 3). Idiopathic BMS most often affects postmenopausal women (it is up to 7-fold more common in women than in men) with a prevalence varying between 0.7% to 7% or more.[7]

A few reports have suggested a link between BMS, central dopamine deficiency, and PD. The prevalence of BMS in a PD population was examined by administering a mail survey to individuals registered to the

Parkinson's Disease Society of Northern Ireland; the survey yielded a prevalence rate of 24%,[8] a figure possibly up to 34-fold higher than in the general population. A case study reported a PD patient who experienced relief of BMS with pramipexole after showing aggravation of symptoms with carbidopa/levodopa[9]; another case of idiopathic BMS was also improved with pramipexole.[10] Decreased dopamine-mediated central inhibition has been suggested as a potential mechanism in BMS, supported by positron emission tomography (PET) scan results showing reduced fluorodopa uptake capacity and increased dopamine D2 receptor binding levels in the putamen.[11,12] Furthermore, both BMS and PD share autonomic nervous system dysfunction.[13] Several aspects related to the relationship between BMS and PD, its characterization as a nonmotor or premotor feature of PD, and its possible augmentation with antiparkinsonian drug therapy need further investigation. Therefore, the goal of this study was to determine the prevalence and characteristics of BMS in a PD population through a self-administered, custom-made survey. There is no standard or ideal tool to screen for BMS. Different neuropathic pain questionnaires have been used previously, such as the PainDETECT and the Douleur Neuropathique 4 questionnaire and its abbreviated version (DN4, DN4i), with variable sensitivity and specificity values to detect BMS.[14] In order to keep the self-administered questionnaire brief and to collect information about BMS, PD-related symptoms, and oral and general health issues, BMS is characterized in the patient population by using a survey developed by the investigators.

Materials and Methods

Participants

The study was conducted in Movement Disorders Clinics of university hospitals in Montreal and Toulouse and was approved by the local ethics committees. Between December 2013 and June 2014, all patients with idiopathic PD who had a follow-up outpatient clinic appointment were solicited upon arrival at the reception desk to fill out a survey on the premises, without pressure or obligation to do so. No other preselection criteria were applied. Filled surveys were given to the neurologist by the patients at the time of their routine examination in order to confirm the diagnosis of PD based on the conventional definition of the UK Parkinson's Disease Society Brain Bank and to ensure the medication profile was properly listed. The neurologist also indicated the Hoehn-Yahr stage of severity and the Schwab & England Activities of Daily Living Scale score. Surveys from those with an alternative diagnosis such as drug-induced parkinsonism or atypical parkinsonism were rejected.

Survey

The anonymous survey was developed by the investigators and consisted of 42 multiple-choice questions. This survey took 20 minutes to complete. The cover page provided a comprehensive description of the research project. Completion of the questionnaire was considered as consent to take part in the study. Participants could get help from a caregiver or a neurologist for clarifications. A general query inclusive of different abnormal chronic oral sensations was first proposed, excluding known sources of oral (eg, dental) pain: "Do you suffer from unexplained chronic oral pain or burning affecting parts of your mouth (tongue, lips, palate, cheek) without any infection, injury, or apparent relation to a dental problem?" Those answering positively needed to address 16 more questions related to the localization, description, intensity, daily profile, and duration of the oral pain condition, as well as its relation with the onset of PD, antiparkinsonian drug intake, or presence of motor fluctuations. All participants provided basic information on their experience with PD and the presence or absence of fluctuations, dyskinesias, restless legs syndrome (RLS), and chronic craniofacial, back, and limb pain. These features were drafted in layman's terms to enhance the participant's understanding. RLS is typically difficult to describe and was broadly defined as the presence of pins and needles, itching, pulling sensations, or discomfort predominating in the legs while sitting or lying down, typically during the evening/nighttime, with an urge to move. Visceral pain and dysautonomia were not addressed. Specific queries pertaining to the orodental condition included the number of natural teeth, wearing of prostheses, presence of xerostomia and excessive thirst sensation, taste abnormality, and purposeless oral behaviors (eg, bruxism, tongue movements, sucking, chewing habits).

Statistical Analyses

The number of surveys collected at each site was based on a previous study.[8] In order to raise specificity, participants reporting chronic oral pain of a nonburning quality were excluded. Answers to the survey questions were transcribed to an Excel database to compare BMS and non-BMS groups. The investigators also developed a poor oral health index (POHI) and an oral habits score (OHS), considering that oral health is compromised in PD by increased prevalence of caries and periodontal disease causing tooth loss, xerostomia, and taste impairment, among other problems.[15] The calculations of these indices were based on weighing factors in proportion to their perceived importance in relation to pain. The POHI (0–104 points) was calculated using the formula: 64 – (2 × number of natural teeth) – denture subscore (32 points for two dentures, 16 for one denture, 6 for two bridges, 3 for

Table 1 Demographic and Basic Parkinson's Disease Data of Participants With and Without BMS

Data	BMS (n = 8)	Non-BMS (n = 190)
Women (%)	87.5	41.1*
Postmenopausal (%)	85.7	93.5
Mean age (± SD)	69.0 (10.3)	68.2 (9.6)
Median PD duration interval (y)	6–10	6–10
Motor fluctuations (%)	66.7	64.4
Dyskinesias (%)	50.0	52.7
Median Hoehn & Yahr stage	3	2.5
Median Schwab & England scale score	60	80
Autonomy for drug self-administration (%)	87.5	79.5
Levodopa replacement therapy (%)	87.5	87.9
Dopamine agonist therapy (%)[a]	25.0	39.5
Mean LEDD (mg)	630.1	653.9

SD = standard deviation; LEDD = levodopa equivalent daily dose.
[a]Dopamine agonists = pramipexole, ropinirole, rotigotine, piribedil, apomorphine.
*Statistically significant difference between groups ($P < .05$).

Table 2 Comparison Between Participants With and Without BMS

	Entire cohort (n = 198)	BMS (n = 8)	Non-BMS (n = 190)
Oral condition			
Edentulism (%)	11.6	0	12.1
Mean Poor Oral Health Index	32.9	49.0	32.2*
Oral Habits Score	4.8	14.3	4.4*
General health condition			
Chronic extraoral pain (%)	74.2	100	73.2
TMJ	9.5	62.5	6.5*
Masticatory muscles	3.4	37.5	1.4*
Neck	6.8	37.5	5.0*
Low back	53.7	62.5	53.2
Limbs	46.9	75.0	45.3
History of depression (%)	28.4	62.5	27.0*
Current use of antidepressants (%)	23.9	25.0	23.8
Diabetes (%)	5.6	25.0	4.8
Restless legs (%)	52.2	100	50.0*

*Statistically significant difference between groups ($P < .05$).

one bridge) + mouth subscore (18 points for xerostomia, 12 points for excessive thirst sensation, 3 points for abnormal or bitter taste).

The OHS (0–51 points) was generated as follows: 15 points for jaw clenching or grinding, 6 points for rubbing or pushing tongue against teeth, and 3 points for sucking or chewing lip, mucosa, or tongue. The levodopa equivalent daily dose (LEDD) was calculated as previously described[16]: levodopa dose + levodopa dose × 1/3 if on entacapone + levodopa dose × 0.67 if on long-acting preparation + pramipexole (mg) × 67 + ropinirole or rotigotine (mg) × 20 + piribedil (mg) + apomorphine (mg) × 8. Ordinal data from BMS and non-BMS participants were compared using the independent samples Mann-Whitney U test, and nominal data compared with the two-sided exact Fisher test (SPSS 23 software). Missing or "I don't know" answers were excluded.

Results

A log was not kept of all the PD outpatients who declined to complete the survey. Since no preselection criteria other than a diagnosis of PD were used, there is no reason to believe that there was a bias against subjects with BMS. A total of 218 surveys were collected and 15 were discarded due to alternative underlying diagnoses (ie, atypical parkinsonism and drug-induced parkinsonism). The answers from 203 participants (87 females and 116 males), half from each clinic, were analyzed. Only five answers were missing. Overall, 13 individuals (6.4%) reported chronic nondental oral pain, with a proportion three-fold higher in women than in men (10.3% vs 3.4%). Five of the individuals (38.5%) reported oral pain of a nonburning quality and were excluded from further analysis. Thus, eight subjects were included in the BMS group, representing a prevalence of BMS of 4.0% (95% confidence intervals [CI]: 2.1–7.8).

Apart from a marked female predominance (seven females and one male) in the BMS group, demographics and basic PD data and treatment were comparable between the BMS and non-BMS groups (Table 1). Oral and general health conditions differed between groups (Table 2). The mean POHI (49.0 vs 32.2 points, $P < .05$) and mean OHS (14.3 vs 4.4 points, $P < .05$) values were higher in the BMS group compared to the non-BMS group. Purposeless oral habits were reported by 75% of the BMS subjects. Xerostomia (87.5% in BMS, 54.7% in non-BMS; $P = .081$) and dysgeusia (37.5% in BMS, 29.1% in non-BMS; $P = .0695$) were common complaints in both groups. In contrast to the low prevalence of BMS, chronic extraoral pain was experienced by nearly three quarters of the participants and by all BMS subjects. Low back pain and limb pain (small or large joints) were reported by 45% to 75% of participants without significant differences between groups. Of note, BMS coexisted with

RLS (100%) and with pain localized to the temporomandibular joint (TMJ) (62.5%), masticatory muscles (37.5%), and neck (37.5%). The BMS group included a greater proportion of subjects with a past history of depression compared to the non-BMS group (62.5% vs 27.0%, $P < .05$), but current antidepressant drug use was similar between groups.

The chronic burning in the BMS group (n = 8) was at least moderate in intensity and not necessarily present every day (Table 3). It variably affected the tongue, floor of the mouth, jaw, anterior palate, and oral mucosa, and was bilateral in six subjects. It had been present for 1 to 5 years in four subjects. BMS occurred after PD onset in seven subjects and fluctuated with other PD symptoms during the day in three subjects. It was not relieved with antiparkinsonian drug intake during the day, but was relieved with ongoing oral activity in four subjects.

Table 3 Characteristics of Oral Pain in the BMS Group (n = 8)

Pain feature	Descriptors (no.)
Pattern during the day	Not everyday (4), persistent (3), increasing (1), night only (1)
Intensity	Moderate (6), very strong (2)
Localization	Entire tongue (5), anterior palate (3), inferior and superior gingiva (3), jaw (3), floor of mouth (4), teeth (1), interior of cheek (1), tip of tongue (1)
Affected side	Always bilateral (6), left only (2)
Duration	1–5 y (4)
Oral health	Wearing of prosthesis or bridge (7), purposeless oral habits (6), xerostomia (7), dysgeusia (3)
Onset in relation to PD	Pain not present before PD (7), variation of pain with PD symptoms (3)
Response to PD medications	Relief (0), no response (3), unsure (2), increased (2)
Relief with oral activity	While eating (4), drinking (4), talking (1)
Restless legs syndrome	Present (8)
Chronic extraoral pain	Present (8)

Discussion

Little data are available about oral pain in PD. Chronic oral pain may be burning in quality or not, as the present findings illustrate. Nonburning pain may be related to atypical odontalgia, chronic myofascial pain, neuropathic pain, and stomatitis. Thus, participants reporting nonburning pain were excluded in the present study. In contrast to the common occurrence of chronic extraoral pain, BMS was found only in a small fraction (4.0%) of PD patients in this PD population. This represents one-sixth of the prevalence value obtained previously in a smaller PD cohort surveyed by mail in Northern Ireland.[8] This low prevalence and clear female predominance do not indicate BMS as a somatosensory feature of PD. However, the occurrence of BMS after PD onset is in agreement with the Northern Ireland mail survey. The present findings are also consistent with the conclusion of Clifford et al[8] regarding the possibility that BMS may be influenced by medication intake, resulting for instance from an augmentation effect such as that seen in RLS or from levodopa-associated sensory neuropathy with vitamin B12 deficiency, as documented recently.[17] However, the latter hypothesis would hardly explain the gender predominance found in the BMS group in the present study. Nonetheless, the constant coexistence of BMS with RLS is of potential importance and could suggest a link with the dopamine system. The presence of purposeless oral habits in 75% of the BMS subjects in the present study is consistent with the proportion of 61% found in another study on BMS conducted in 84 patients (85% female).[18] The higher mean OHS value in BMS subjects found in the present study would also support a common substrate with RLS, as suggested previously.[10]

The diagnosis of BMS requires a detailed examination to exclude oral (eg, dental, prosthetic, mucosal) pathology, a critical step that was not undertaken in this outpatient survey. In contrast to typical idiopathic BMS, daily and continuous (or nearly continuous) burning was not a universal feature in the BMS group of the present study. BMS in PD was associated with a higher mean POHI value compared to non-BMS patients, calling for a formal examination of the oral cavity and dentures necessary to identify potential sources for secondary BMS. No apparent relation was found between the proportion of edentulism or denture wearing and BMS, as observed previously,[8] but other possible relevant features such as denture design, retention, condition, and microbial colonization were not addressed. Xerostomia and dysgeusia are often described in idiopathic BMS and were common in the present study as well, somewhat more in the BMS participants. Trigeminal small-fiber sensory neuropathy has been suggested as a BMS mechanism in a tongue biopsy study of 12 subjects with BMS,[19] perhaps in relation to herpes virus reactivation.[20] It could also occur in some PD patients, but one would reasonably expect the resulting pain to manifest daily and persistently, unlike in four of the BMS patients in the present study. Since the study participants were not queried specifically about dysautonomia, such features cannot be used as supportive evidence for a neuropathic process.

Some relevant general health issues were raised in the present study's survey. A history of depression was more commonly reported in the BMS group. Interestingly, BMS has been attributed to serotonin-selective reuptake inhibitor intake in a woman without apparent glossitis.[21] Thus, even though the current use of antidepressants in the present study was similar between BMS and non-BMS groups, a possible drug-induced origin beyond antiparkinsonian medication cannot be overlooked. Chronic extraoral pain was common in both groups alike and a constant feature in the BMS participants, in agreement with other studies and with the activation of central nociceptive pathways previously documented in PD.[5] The relatively high prevalence of craniocervical pain (temporomandibular joint, masticatory muscles, and neck) found in the BMS group is intriguing, but its significance remains undetermined. The coexistence of BMS with visceral pain is unclear since this aspect was not addressed in the survey. Further analysis of the relations between BMS and PD is limited by the self-reporting study design, nonvalidated pain survey, small cohort size, and lack of oral examination and laboratory results.

Conclusions

In contrast to previous findings, the custom-made survey administered to nonselected outpatient PD subjects yielded a low prevalence of BMS. BMS was almost exclusively in women and nearly always manifested after PD onset, not always in a daily or continuous fashion, and always coexisted with RLS. Although a diagnosis of idiopathic BMS cannot be excluded in these patients, a possible link with antiparkinsonian drug therapy cannot be rejected, as suggested previously.[8,9] Since BMS subjects showed a higher mean POHI value relative to non-BMS subjects, they should be consistently referred to a dentist to rule out oral or denture problems.

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Survey on a subtype of chronic oral pain called burning mouth syndrome in Parkinson's disease

Madam, Sir,

At least one-half of patients literally suffer from Parkinson's disease. Pain may be present at any stage of the illness. This survey is about « burning mouth syndrome », a special type of chronic oral pain which is not of dental origin (on a tooth abscess for example), causing an unexplained burning sensation in the mouth without any obvious lesion (the mouth looks healthy otherwise). Your answers will allow researchers to better understand the significance of this subtype of chronic pain in the context of Parkinson's disease.

ALL patients living with the typical or conventional form of Parkinson's disease are invited to participate, not only those who do experience chronic oral pain. Your answers will reflect your consent to the study. This survey is anonymous, your name will not appear anywhere. Your participation is voluntary, you can refuse to participate without any justification or loss in your privileges and rights. We ask you not to complete the survey if you are uncertain about the diagnosis of Parkinson's disease, or if you have obvious mouth lesions such as thrush or ulcers.

This survey is conducted in partnership with the University Hospitals of Montreal (CHUM) and Toulouse. All answers will be transferred to a computer databank and kept in Montreal for 10 years.

We thank you for your collaboration.

With best regards,

Pierre Blanchet, MD, FRCPC, PhD
Neurologist, CHU Montreal

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1. You are:

   ❑ WOMAN ❑ MAN

2. How old are you?_____

3. If you are a woman, are you postmenopausal?

   ❑ YES ❑ NO

4. Do you suffer from unexplained **chronic oral pain or burning** affecting parts of your mouth (tongue, lips, palate, cheek) without any infection, injury, or apparent relation to a dental problem?

   ❑ YES – Go to the next question
   ❑ NO – Go to question #21

5. Your chronic oral pain not of dental origin (please check all that apply):

   ❑ is absent (or minor) upon awakening and worsens throughout the day to peak in intensity in the evening
   ❑ is already present upon awakening and persists throughout the day
   ❑ is not present everyday
   ❑ is absent overnight
   ❑ is present at night enough to wake me up

6. Which structure is painful in your mouth (please check all that apply)?

   ❑ tip of the tongue only
   ❑ entire tongue or so
   ❑ front part of the palate
   ❑ lower lip
   ❑ upper lip
   ❑ upper gingiva
   ❑ lower gingiva
   ❑ inside of the cheek

- ❑ jaw
- ❑ one tooth or more
- ❑ floor of the mouth (under the tongue)

7. Your chronic oral pain is present (check one only):

   - ❑ <u>always</u> on the same side (right ❑ left ❑)
   - ❑ sometimes on the right, sometimes on the left
   - ❑ <u>always</u> on both sides

8. Which of the following descriptive word best describes your chronic oral pain (check the choice that fits best your pain experience)?

   - ❑ burning
   - ❑ scalding
   - ❑ numb feeling
   - ❑ tingling
   - ❑ discomfort
   - ❑ like a toothache
   - ❑ tearing
   - ❑ crushing
   - ❑ pulling
   - ❑ other

9. How would you generally rate the intensity of your chronic oral pain (check the choice that fits best your pain experience)?

   - ❑ minimal
   - ❑ slight
   - ❑ moderate
   - ❑ severe
   - ❑ very severe

What is the average intensity of your chronic oral pain at different periods of the day? Provide a value between 0 [no pain] and 10 [extreme, unbearable pain] according to the pain experienced at specific times:

	Hour	Pain intensity (scale from 0 to 10)					
10	At 9 o'clock in morning?	○0	○1	○2	○3	○4	○5
		○6	○7	○8	○9	○10	
11	At 3 o'clock in afternoon?	○0	○1	○2	○3	○4	○5
		○6	○7	○8	○9	○10	
12	At 9 o'clock in evening?	○0	○1	○2	○3	○4	○5
		○6	○7	○8	○9	○10	
13	At 3 o'clock at night?	○0	○1	○2	○3	○4	○5
		○6	○7	○8	○9	○10	

14. How long have you experienced chronic oral pain (check the choice that fits best your pain experience)?

- ❑ less than 3 months
- ❑ between 3 to 6 months
- ❑ between 7 to 12 months
- ❑ between 1 to 5 years
- ❑ between 6 to 10 years
- ❑ over 10 years

Please answer YES or NO to the following questions (check the corresponding circle):

	Question	Yes	No
15	Is your oral pain relieved (or absent) while eating?	○1	○2
16	Is your oral pain relieved (or absent) while drinking cold water?	○1	○2
17	Is your oral pain relieved (or absent) while talking?	○1	○2

18. Have you ever been treated with a specific approach in order to relieve your chronic oral pain?

    ❑ yes, with the following agents (check all that apply)?
    ○Lipoic acid ○Clonazepam (Rivotril, Klonopin) ○Amitryptiline (Elavil, Laroxyl) ○Gabapentin (Neurontin) ○ Pregabalin (Lyrica) ○Capsaïcin ○Anti-inflammatory (aspirin, ibuprofen, naproxen) ○Minor analgesics (acetaminophen, paracetamol) ○Strong analgesics (codein, morphine, hydromorphone, oxycodone, Tramadol) ○Marijuana

    ❑ yes, by replacing my denture(s)
    ❑ no, I do not recall

19. If you have been treated for chronic oral pain not of dental origin, were you relieved of that pain?

    ❑ yes, clearly
    ❑ no, not at all
    ❑ partially

20. Is your chronic oral pain at least partly relieved by the intake of your Parkinson's pills during the day?

    ❑ yes
    ❑ no
    ❑ uncertain
    ❑ on the opposite, oral pain is worsened with those pills

GENERAL HEALTH CONDITION

21. How long ago were you diagnosed with Parkinson's disease?

    ❑ under 6 years
    ❑ 6 to 10 years
    ❑ 11 to 15 years
    ❑ 16 to 20 years
    ❑ over 20 years

22. Which side of your body is most affected by Parkinson's disease?

- ❑ right
- ❑ left
- ❑ uncertain

23. Were you experiencing chronic oral pain even BEFORE the first signs of Parkinson's disease became apparent?

- ❑ yes; if so, how many years before?_____ years
- ❑ no
- ❑ uncertain
- ❑ I have no chronic oral pain

24. Do you experience periods in which your Parkinson's symptoms reappear during the day (for instance when it is time to take your pills)?

- ❑ yes clearly
- ❑ no
- ❑ I do not know

25. Do you experience **dyskinesia** during the day, with abnormal involuntary movements involving your head, arms, legs, or trunk, occurring against your self-control and will? (Please note that such movements are distinct from tremor activity.)

- ❑ yes
- ❑ no
- ❑ uncertain

26. Did you ever notice that the intensity of your chronic oral pain varies or fluctuates with the level of control of your Parkinson's symptoms, whereby your oral pain is more severe when your Parkinson's tremor, stiffness, slowness, and gait difficulty, reappear during the day?

- ❑ yes clearly

- ❑ no
- ❑ I do not know
- ❑ I have no chronic oral pain

27. How many natural teeth do you have in your mouth?_____

28. Concerning your dental condition (check all that apply):

- ❑ I am edentulous (no natural teeth) at the upper jaw
- ❑ I am edentulous (no natural teeth) at the lower jaw
- ❑ I wear one removable partial denture
- ❑ I wear two removable partial dentures
- ❑ I wear one fixed bridge (permanent restauration replacing missing teeth)
- ❑ I regularly wear one full denture
- ❑ I regularly wear two full dentures

29. Do you **<u>often</u>** have the habit of moving or contracting one part of your mouth during the day (check all that apply)?

- ❑ I press my tongue against the front teeth
- ❑ I push my tongue between two teeth
- ❑ I clench my jaw
- ❑ I grind my teeth during the day
- ❑ I suck a tooth or my denture
- ❑ I chew my tongue, my lips, or my cheek
- ❑ no, I have no habits of that kind

Reflecting upon your general health condition (check the corresponding circle):

	Condition	**Yes**	**No**
30	Is your mouth <u>often</u> dry?	○1	○2
31	Do you <u>often</u> have a bitter or metallic taste in your mouth?	○1	○2
32	Are you <u>often</u> thirsty?	○1	○2
33	Do you find difficult tasting the foods and drinks you take?	○1	○2

34	Do you have diabetes?	○1	○2
35	Have you ever suffered from a depression?	○1	○2
36	Do you currently take an antidepressant drug?	○1	○2
37	Are you treated for anemia?	○1	○2

38. Do you experience **restless legs**, with tingling, ants-crawling, or pulling sensations, or an unpleasant discomfort, predominating in your legs while sitting quiet or lying in bed, with an urge to move them in order to find relief, particularly during the evening and nighttime?

- ❑ yes
- ❑ no
- ❑ uncertain

39. Do you <u>regularly</u> (meaning everyday or several days a week) suffer from pain outside the mouth area?

- ❑ yes; if so, check all that apply:
    - ❑ head
    - ❑ jaw joint in front of the ear
    - ❑ jaw muscles
    - ❑ front of the neck
    - ❑ back of the neck
    - ❑ arm
    - ❑ low-back area
    - ❑ legs
    - ❑ large limb joints (shoulder, hip, knee)
    - ❑ small limb joints (wrist, hand, ankle, toes)
    - ❑ genital area
- ❑ no (go to question #41)

40. Is your body pain worsening in intensity when your Parkinson's symptoms reappear during the day?

- ❑ yes
- ❑ no
- ❑ uncertain

41. Do you self-manage your drug administration during the day?

❑ YES ❑ NO

42. Using the table below, please check **ALL** the pills you take to manage your Parkinson's disease.

NAME	**DOSE**	**DAILY INTAKE (number of pills/day)**				
Levodopa/carbidopa	100/25	O_1	O_2	O_3	O_4	O_5
		O_6	O_7	O_8	O_9	O_{10}
		O_{11}	O_{12}	O_{13}	O_{14}	O_{15}
		O_{16}	O_{17}	O_{18}	O_{19}	O_{20}
		O_{21}	O_{22}	O_{23}	O_{24}	O_{25}
Levodopa/benserazide (Prolopa, Madopar)	50/12.5	O_1	O_2	O_3	O_4	O_5
		O_6	O_7	O_8	O_9	O_{10}
		O_{11}	O_{12}	O_{13}	O_{14}	O_{15}
		O_{16}	O_{17}	O_{18}	O_{19}	O_{20}
Levodopa/benserazide (Prolopa, Madopar)	100/25	O_1	O_2	O_3	O_4	O_5
		O_6	O_7	O_8	O_9	O_{10}
		O_{11}	O_{12}	O_{13}	O_{14}	O_{15}
		O_{16}	O_{17}	O_{18}	O_{19}	O_{20}
		O_{21}	O_{22}	O_{23}	O_{24}	O_{25}
Levodopa/benserazide (Madopar)	200/50	O_1	O_2	O_3	O_4	O_5
		O_6	O_7	O_8	O_9	O_{10}
Levocarb-CR (Sinemet-CR)	100/25	O_1	O_2	O_3	O_4	O_5
		O_6	O_7	O_8	O_9	O_{10}
		O_{11}	O_{12}	O_{13}	O_{14}	O_{15}
		O_{16}	O_{17}	O_{18}	O_{19}	O_{20}
Levocarb-CR (Sinemet-CR)	200/50	O_1	O_2	O_3	O_4	O_5
		O_6	O_7	O_8	O_9	O_{10}
Stalevo	50/12.5/200	O_1	O_2	O_3	O_4	O_5
		O_6	O_7	O_8	O_9	O_{10}
Stalevo	75/18.75/200	O_1	O_2	O_3	O_4	O_5
		O_6	O_7	O_8	O_9	O_{10}
Stalevo	100/25/200	O_1	O_2	O_3	O_4	O_5
		O_6	O_7	O_8	O_9	O_{10}
Stalevo	125/31.25/200	O_1	O_2	O_3	O_4	O_5
		O_6	O_7	O_8	O_9	O_{10}

Stalevo	150/37.5/200	O_1	O_2	O_3	O_4	O_5
		O_6	O_7	O_8	O_9	O_{10}
Entacapone (COMTAN)	200 mg	O_1	O_2	O_3	O_4	O_5
		O_6	O_7	O_8	O_9	O_{10}
Pramipexole (Mirapex, Mirapexin)	0.25 mg	O_1	O_2	O_3	O_4	O_5
		O_6	O_7	O_8	O_9	O_{10}
		O_{11}	O_{12}	O_{13}	O_{14}	O_{15}
		O_{16}	O_{17}	O_{18}	O_{19}	O_{20}
Pramipexole	0.5 mg	O_1	O_2	O_3	O_4	O_5
		O_6	O_7	O_8	O_9	O_{10}
Pramipexole	0.75 mg	O_1	O_2	O_3	O_4	O_5
		O_6	O_7	O_8	O_9	O_{10}
Pramipexole	1 mg	O_1	O_2	O_3	O_4	O_5
Pramipexole	1.5 mg	O_1	O_2	O_3	O_4	O_5
Ropinirole (ReQuip)	0.25 mg	O_1	O_2	O_3	O_4	O_5
		O_6	O_7	O_8	O_9	O_{10}
		O_{11}	O_{12}	O_{13}	O_{14}	O_{15}
		O_{16}	O_{17}	O_{18}	O_{19}	O_{20}
Ropinirole	1 mg	O_1	O_2	O_3	O_4	O_5
		O_6	O_7	O_8	O_9	O_{10}
		O_{11}	O_{12}	O_{13}	O_{14}	O_{15}
		O_{16}	O_{17}	O_{18}	O_{19}	O_{20}
Ropinirole	2 mg	O_1	O_2	O_3	O_4	O_5
		O_6	O_7	O_8	O_9	O_{10}
		O_{11}	O_{12}	O_{13}	O_{14}	O_{15}
Ropinirole	5 mg	O_1	O_2	O_3	O_4	O_5
Amantadine (Symmetrel)	100 mg	O_1	O_2	O_3	O_4	O_5
Rasagiline (Azilect)	0.5 mg	$O_{½}$	O_1	O_2		
Rasagiline	1 mg	$O_{½}$	O_1	O_2		
Selegiline (Eldepryl)	5 mg	$O_{½}$	O_1	O_2		
Trihexiphenidyl	2 mg	O_1	O_2	O_3	O_4	O_5
		O_6	O_7	O_8	O_9	O_{10}
Procyclidine (Kemadrin)	2.5 mg	O_1	O_2	O_3	O_4	O_5
		O_6	O_7	O_8	O_9	O_{10}
Procyclidine	5 mg	O_1	O_2	O_3	O_4	O_5
Benztropine (Cogentin)	1 mg	O_1	O_2	O_3	O_4	O_5
Benztropine	2 mg	O_1	O_2	O_3	O_4	O_5

Thank you very much for participating in this survey.

SECTION TO BE COMPLETED BY YOUR NEUROLOGIST:

MODIFIED HOEHN & YAHR STAGING

- ❑ Stade 0 : No signs of disease.
- ❑ Stade 1 : Unilateral disease.
- ❑ Stade 1,5 : Unilateral plus axial involvement.
- ❑ Stade 2 : Bilateral disease, without impairment of balance.
- ❑ Stade 2,5 : Mild bilateral disease, with recovery on pull test.
- ❑ Stade 3 : Mild to moderate bilateral disease; some postural instability; physically independent.
- ❑ Stade 4 : Severe disability; still able to walk or stand unassisted.
- ❑ Stade 5 : Wheelchair bound or bedridden unless aided.

SCHWAB & ENGLAND ACTIVITIES OF DAILY LIVING SCALE

- ❑ 100% : Completely independent. Able to do all chores without slowness, difficulty or impairment. Essentially normal. Unaware of any difficulty.
- ❑ 90% : Completely independent. Able to do all chores with some degree of slowness, difficulty or impairment. Might take twice as long. Beginning to be aware of difficulty.
- ❑ 80% : Completely independent in most chores. Takes twice as long. Conscious of difficulty and slowness.
- ❑ 70% : Not completely independent. More difficulty with some chores. Three to four times as long in some. Must spend a large part of the day with chores.
- ❑ 60% : Some dependency. Can do most chores, but exceedingly slowly and with much effort. Errors; some impossible.
- ❑ 50% : More dependent. Help with half of chores, slower, etc. Difficulty with everything.
- ❑ 40% : Very dependent. Can assist with all chores, but few alone.
- ❑ 30% : With effort, now and then does a few chores alone or begins alone. Much help needed.
- ❑ 20% : Nothing alone. Can be a slight help with some chores. Severe invalid.
- ❑ 10% : Totally dependent, helpless. Complete invalid.
- ❑ 0% : Vegetative functions such as swallowing, bladder and bowel functions are not functioning. Bedridden.