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Nonmotor symptoms of Parkinson's disease: Prevalence and awareness of patients and families

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Abstract

The aim of this study was to explore the prevalence of nonmotor symptoms in Parkinson's disease (PD) and the patients' and family members' awareness of these symptoms. We evaluated 74 parkinsonian patients and 54 family members. Seventy-three patients had more than one symptom (12.4±5.5 out of 30 symptoms on average). Nocturia was the most common in men and feeling sad in women. The average number of symptoms which patients knew to be related to PD was 5.2±6.8 and to family members 7.7±6.5. Twenty-eight patients and five family members were unaware of the relationship between any of these symptoms and PD. For PD to be properly managed, nonmotor symptoms should be comprehensively assessed and patients and families informed that these are associated with PD.

Keywords: Parkinson's disease; Nonmotor; Awareness

1. Introduction

The nonmotor symptoms of Parkinson's disease(PD) have been described since they were first reported by James Parkinson [1]. However, they have been largely neglected by both physicians and patients compared to the typical motor symptoms, which are the main symptoms corresponding to the criteria for the diagnosis [2]. In fact, PD patients report many nonmotor symptoms, such as cognitive dysfunctions, psychiatric disturbances, sleep disorders, dysautonomia, and sensory symptoms, which can be explained by wide pathological alterations beyond the substantia nigra in PD [3,4]. These nonmotor symptoms can cause problems in the daily life of patients and have as great an impact on the quality of life as the motor symptoms [5,6]. Recently there have been many researchers who advocate a comprehensive approach to nonmotor symptoms, and interest is increasing thanks to their efforts [7,8].

Despite these efforts, the reason that nonmotor symptoms are not adequately treated must be because they are not as obvious as motor symptoms. One of the major reasons that nonmotor symptoms are not adequately managed is that patients and their families may not be aware of the connection of their nonmotor symptoms to their disease. If the patients or their family members are aware that such symptoms are caused by or related to PD, they will complain about these symptoms, and the doctor will try to manage the symptoms appropriately. This will also save unnecessary tests and treatments due to misdiagnosis.

On the assumption that interest in the nonmotor symptoms of PD may depend on the awareness of the patients and their families, this study attempted to determine how frequent nonmotor symptoms are and how aware the patients and their family members are of the relationship between nonmotor symptoms and PD.

2. Subjects and methods

2.1. Subjects

We evaluated 74 consecutive patients who had been diagnosed with PD under the diagnostic criteria of Gelb et al. [9] and 54 family members. All

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patients had been treated with dopaminergic therapy. All patients and family members in this study provided written informed consent.

2.2. Methods

A survey of the nonmotor symptoms was carried out using a translated version of the patient questionnaire introduced in a recent study on NonMotor Symptoms Questionnaire (NMSQuest study) by qualified translators [10]. The questionnaire consisted of 30 items. Patients and family members were asked to answer 'Yes' or 'No' for each symptom mentioned in each question. Also, we evaluated Hoehn and Yahr (H–Y) stage, mini-mental status examination (MMSE) and duration of parkinsonian symptoms of the patients and divided patients to rigid and tremor group according to dominant symptoms at disease onset.

In addition, we added a question to ask whether the respondent recognized that the symptoms related to PD. To determine whether the awareness of the relationship between the nonmotor symptoms and PD correlated with the educational level of all the subjects, we also asked the duration of education.

2.3. Statistical analysis

We used Fisher's exact tests to compare the frequency and the awareness of nonmotor symptoms according to clinical characteristics, and nonparametric Spearman test to define that those were correlated with H–Y stage, MMSE, duration of disease, and education period with the help of SPSS 12.0 (SPSS Inc., Chicago, USA). p Values of less than 0.05 were accepted as significant.

3. Results

3.1. Prevalence of nonmotor symptoms

Seventy-four patients (28 males and 46 females, age 64.9±8.6 years) participated. H–Y stage of the patients ranged from 1.5 to 3, and their average duration of parkinsonian symptoms was 6.4±6.1 years (Table 1).

The most frequent nonmotor symptom was nocturia (67.6%). It was followed by restless legs, constipation, feeling sad, orthostatic dizziness, and memory disturbance, of which more than 60% of the patients complained. The least frequent nonmotor symptoms were bowel incontinence, delusions, and hallucinations (Table 2).

There were no significant differences in age, duration of parkinsonian symptoms, and H–Y stage between male and female groups. The nonmotor symptoms most frequently complained of by male patients in order of frequency, were nocturia, restless legs, constipation, orthostatic dizziness, and excessive sweating, while female patients reported feeling sad, insomnia, memory disturbance, and constipation. The frequency of drooling of saliva, change in sexual interest, and sexual dysfunction was significantly higher in male patients than in female patients, and female patients complained insomnia more frequently.

When the patients were divided into rigid and tremor groups according to their dominant symptom at the time of disease onset, the tremor group was 41 (15 males) and the rigid group was 33 (13 males). There were no significant differences in other clinical characteristics between the two groups. The tremor group complained, in order of frequency, of restless legs, memory disturbance, constipation, nocturia, and orthostatic dizziness, while the rigid group complained of feeling sad, nocturia, excessive sweating, orthostatic dizziness, constipation, and unexplained pain. Patients in the rigid group complained unexplained pain more frequently (62.5% vs 39%), but this did not reach statistical significance.

All patients except one had more than one nonmotor symptom and they had 12.4±5.5 symptoms on average. This frequency of symptoms did not correlate with the age, H–Y stage, or duration of PD symptoms, and there were no differences according to sex or dominant symptom at onset.

Table 1
Demographics of patients and family members

	Patients ($n = 96$)	Family members ($n = 54$)
Male:female	28:46	20:34
Age (yr)	64.9±8.6	50.6±14.9
Education (yr)	8.6±4.3	11.4±4.5
MMSE	25.8±3.3	
Hoehn and Yahr stage	1.5–3 (Median 2.5)	
Duration of disease (yr)	6.4±6.1	

Data are presented as mean±SD unless otherwise indicated.

3.2. Awareness of the relationship between nonmotor symptoms and PD

As to the question whether they were aware of the relationship between nonmotor symptoms and PD, the patient group was most aware of drooling of saliva (31.9%), followed by memory disturbance, constipation, orthostatic dizziness, and falling. More than 25% of the patients were aware of the relationship between these symptoms and PD. The least known symptoms were delusions, bowel incontinence, and parasomnias; less than 10% of the patients were aware of these symptoms. However, there was no single symptom that all the patients failed to relate to their PD (Table 3).

Twenty-eight patients answered that they were unaware of the relationship between any of the 30 symptoms and PD. The average number of symptoms the patients recognized to be related to PD was 5.2±6.8. The awareness of the relationship correlated with symptoms the patient had ($r = 0.314$, $p = 0.006$), the duration of the parkinsonian symptoms ($r = 0.293$, $p = 0.011$), and the duration of education ($r = 0.317$, $p = 0.008$).

A survey of the awareness of the patients' family members showed that most recognized symptoms, in order of frequency, were feeling sad, memory disturbance, insomnia, and orthostatic dizziness; no family member was aware of the relationship between sexual dysfunction and PD. The symptoms least recognized by family members were nausea, unexplained pain, and unexplained weight loss. Five family members (9.3%) answered that

Table 2
Prevalence of nonmotor symptoms in patients

Prevalence (%)	Total ($n = 74$)	Male ($n = 28$)	Female ($n = 46$)	p^a	Tremor ($n = 41$)	Rigid ($n = 33$)	p^b
Dribbling of saliva	32.4	50.0	21.7	.020	29.3	36.4	.619
Change in taste/smelling	28.4	32.1	26.1	.604	26.8	30.3	.799
Swallowing difficulty	31.1	28.6	32.6	.797	39.0	21.2	.132
Vomiting, nausea	23.0	21.4	23.9	1	26.8	18.2	.419
Constipation	65.8	67.9	64.4	.805	67.5	63.6	.807
Bowel incontinence	5.4	7.1	4.3	.631	7.3	3.0	.624
Incomplete bowel emptying	39.2	46.4	34.8	.338	43.9	33.3	.473
Urinary urgency	55.4	46.4	60.9	.240	56.1	54.5	1
Nocturia	67.6	78.6	60.9	.133	65.9	69.7	.805
Unexplained pain	49.3	40.7	54.3	.334	39.0	62.5	.061
Unexplained weight loss	35.1	32.1	37	.803	26.8	45.5	.141
Memory disturbance	60.8	53.6	65.2	.338	68.3	51.5	.159
Loss of interest	53.4	50.0	55.6	.810	48.8	59.4	.479
Hallucinations	17.6	17.9	17.4	1	19.5	15.2	.762
Concentrating difficulty	51.4	53.6	50	.814	56.1	45.5	.483
Feeling sad, blues	65.3	53.6	72.7	.129	57.5	75.0	.142
Feeling anxious	47.9	44.4	50	.807	41.0	56.3	.238
Change in sexual interest	34.8	57.7	20.9	.004	39.5	29.0	.449
Sexual dysfunction	37.3	60.0	23.8	.004	35.1	40.0	.801
Orthostatic dizziness	63.9	64.3	63.6	1	62.5	65.6	.810
Falling	37.5	25.0	45.5	.133	37.5	37.5	1
Daytime sleepiness	26.4	21.4	29.5	.585	25.0	28.1	.794
Insomnia	55.6	39.3	65.9	.032	55.0	56.3	1
Intense, vivid dreams	40.3	39.3	40.9	1	37.5	43.8	.635
Sleep talking and moving	34.7	39.3	31.8	.614	42.5	25.0	.142
Restless legs	66.7	71.4	63.6	.611	75.0	56.3	.132
Swelling of legs	30.6	25.0	34.1	.446	27.5	34.4	.610
Excessive sweating	59.7	60.7	59.1	1	52.5	68.8	.227
Double vision	40.8	51.9	34.1	.213	46.2	34.4	.343
Delusions	8.3	10.7	6.8	.672	12.5	3.1	.217

[a] p Value of x^2 in male–female.
[b] p Value of x^2 in tremor–rigid.

they were unaware of the relationship of any of the symptoms. The average number of symptoms the family members recognized was 7.7 ± 6.5. The number of family members who were aware that drooling of saliva, change of taste or smell, and sexual dysfunction were related to PD was significantly fewer than in the patients; some symptoms were more recognized by the family members but the difference did not reach significance. The awareness of nonmotor symptoms by the family members was not related to the duration of education.

4. Discussion

This study used a self-reporting questionnaire for a comprehensive approach to nonmotor symptoms in order to determine how frequently nonmotor symptoms occur in PD patients and how aware they were of the relationship of these symptoms to PD. Chaudhuri et al. [10] selected 50 symptoms of PD based on their research of published studies, surveys of patients, nurses, and family members of the patients, and narrowed them down to 30 symptoms. According to them, to the question that asked whether the PD patients experienced any of the 30 symptoms during the past 1 month, the patients complained of more than 10 symptoms on average, and the number increased the higher the H–Y stage of the patient They reported that over 75% of the family members expected that the survey would help the treatment of the patients. This study also reported that the patient group had significantly more symptoms of drooling of saliva, disturbance of taste or smell, swallowing difficulty, constipation, urinary urgency, unexplained weight loss, concentration difficulty, feeling sad, delusions, feeling anxious, sexual dysfunction, falling, daytime sleepiness, parasomnias, and excessive sweating than the control group.

In our study, the patients complained of more than 12 symptoms on average but there was no association between the number of symptoms and age, H–Y stage, or duration of disease. This might be explained by the fact that most of the patients were mild (H–Y stage of 63 patients were less than 3) and had short disease duration.

The most frequent symptom was nocturia, and its frequency was identical to the previous report, and the order of frequency for other symptoms, i.e., feeling anxious, constipation, feeling sad, orthostatic dizziness, and memory disturbance was similar to the order of frequency in the previous report. The numbers of nonmotor symptoms between male and female patient

Table 3
Awareness of nonmotor symptoms in patients and family members

Awareness (%)	Patients			p^a	Family	p^b
	Total ($n = 74$)	Male ($n = 28$)	Female ($n = 46$)		Total ($n = 41$)	
Dribbling of saliva	31.9	53.6	18.2	.004	10.3	.011
Change in taste/smelling	18.1	28.6	11.4	.114	4.8	.048
Swallowing difficulty	15.1	14.3	15.6	1	7.1	.251
Vomiting, nausea	12.5	10.7	13.6	1	2.4	.091
Constipation	27.8	32.1	25.0	.593	19.0	.370
Bowel incontinence	6.9	3.6	9.1	.642	4.8	1
Incomplete bowel emptying	13.7	21.4	8.9	.168	7.7	.537
Urinary urgency	22.2	25.0	20.5	.773	14.3	.337
Nocturia	16.4	17.9	15.6	1	14.6	1
Unexplained pain	12.7	11.5	13.3	1	4.7	.203
Unexplained weight loss	11.1	21.4	4.5	.049	4.8	.320
Memory disturbance	29.2	28.6	29.5	1	26.2	.830
Loss of interest	17.1	17.9	16.7	1	21.4	.622
Hallucinations	11.1	14.3	9.1	.703	11.9	1
Concentrating difficulty	22.5	25.0	20.9	.774	19.0	.813
Feeling sad, blues	27.8	28.6	27.3	1	26.8	1
Feeling anxious	15.7	18.5	14.0	.739	14.6	1
Change in sexual interest	13.0	2.1	7.0	.072	5.0	.322
Sexual dysfunction	13.4	24.0	7.1	.069	0	.025
Orthostatic dizziness	27.8	32.1	25.0	.593	22.0	.655
Falling	26.8	28.6	25.6	.790	22.0	.654
Daytime sleepiness	15.3	25.0	9.1	.095	14.6	1
Insomnia	22.2	25.0	20.5	.773	23.8	1
Intense, vivid dreams	15.3	28.6	6.8	.019	9.8	.567
Sleep talking and moving	9.7	21.4	2.3	.012	10.0	1
Restless legs	23.6	35.7	15.9	.086	22.5	1
Swelling of legs	13.9	14.3	13.6	1	17.1	.785
Excessive sweating	19.4	25.0	15.9	.373	14.6	.614
Double vision	15.5	25.9	9.1	.090	7.3	.250
Delusions	5.6	7.4	4.5	.632	5.0	1

[a] p Value of x^2 in male–female patients.
[b] p Value of x^2 in patients–family members.

groups or between tremor and rigid group did not differ; however, there was a statistically significant difference in the prevalence of symptoms between male and female patients. This suggests that treatment must be adapted to each individual because their symptoms could be different according to the clinical characteristics. The frequency of nonmotor symptoms experienced by family members was also surveyed just for reference, not for comparison with the patient group. The average age of the family members was 50.6 ± 14.9 and they had 2.9 ± 5.6 symptoms on average. More than 40% of them answered that they had nocturia, orthostatic dizziness, insomnia, memory disturbance, and urinary urgency.

The survey results revealed that both patients and their family members were not very well aware of the relationship between nonmotor symptoms and PD. In particular, it is surprising that as many as 37.8% of the patients did not know at all the nonmotor symptoms in the questionaire were related to PD. Compared to the patients, their family members recognized more symptoms, probably due to the difference in age and education. The more symptoms that the patient experienced and the longer the duration of PD symptoms and education, the more the patients were aware of nonmotor symptoms related to PD. This shows that people understand their disease better the longer they have the symptoms. There was no correlation between the awareness of family members and the duration of education and we suggest that their awareness might be more related to their interest in the patient and the disease. A limitation in our study is that we did not think of investigating the relationship between the patient and family members to correlate the awareness of family members.

Although not mentioned in the results, to the question "What is the main source of your information about disease?" over 90% of the patients and over 60% of the family members answered medical organizations or medical personnel. Over 60% of patients and family members said they wanted to know more about their disease, but over half of these respondents said they could not get reliable information. These results clearly show the responsibility of the physicians who diagnose and treat PD. Even though the authors are working hard for the education of patients and their families and strive for a comprehensive approach to the disease in our center, the results of this study confirm that such efforts are still insufficient.

In this study, the authors found that nonmotor symptoms were prevalent in PD patients and many patients and family members were unaware of the relationship between the nonmotor symptoms and PD. For an appropriate management of PD, including the nonmotor symptoms as well as motor symptoms and the education of patients and families about their disease requires a comprehensive approach.

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