TITLE: **Parkinson's disease: more non-motor symptoms for younger sufferers**
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Parkinson's Disease (PD) is a common neurological disorder that affects about 1.5 million Americans (www.parkinsons.org), affecting their ability to move, speak, and coordinate action. A relatively small proportion (<10%) of PD patients first experience symptoms before the age of 40; these are called Young-Onset Parkinson's Disease patients or YOPD. In addition to the well-known tremor, stiffness and slowness most people associate with PD (referred to as "motor" symptoms), it is now also recognized that patients with PD experience a variety of "non-motor" symptoms too, including hallucinations, sexual dysfunction, and constipation. Many PatientsLikeMe members with PD use their profile to make ad-hoc reports of non-motor symptoms, and can easily share this information with the doctor by accessing their profile or printing a 'doctor visit sheet'.

We decided to use a validated scale developed specifically to screen non-motor symptoms in people with PD, the NMS-Quest (Chaudhuri et al 2007), a self-report questionnaire that consists of 30 items and asks patients to endorse in a simple binary format whether they have experienced a particular non-motor symptom within the past 30 days. We recently reported differences between our population and the original validation population (Wicks et al 2008); we found that PD patients on PatientsLikeMe were more likely than the original validation population to report a variety of non-motor symptoms, especially sexual dysfunction and bowel incontinence, suggesting patients may be more willing to report embarrassing symptoms online rather than to their clinician. As we have a relatively young population of users (<65 on average) we decided to test the hypothesis that patients with the YOPD form of the disease have a more severe progression in terms of non-motor symptoms.

Methods:

The survey was sent in January 2008 to 1,019 registered users on the site. Responses at baseline were received from 307 PD patients (30%), and 28 (3%) patients opted-out of the survey.

Results:

YOPD patients reported a median of 14/30 symptoms relative to PD patients who reported a median of 11/30. This difference was statistically significant ($U=4684.500$, $p=0.019$), and remained so even after controlling for disease duration as a covariate (corrected $F(2)=3.523$, $p=0.031$). At the individual item level, YOPD patients reported apathy, concentration problems, falls, pains, and sadness more often than older onset PD patients.

Table 1: Demographic data

Mean (SD)	**PD**	**YOPD**
N	260	46
% Male	41%	35%
Age	60 (10)	47 (9)
Age at onset	54 (10)	33 (5)
Last UPDRS Section I & II Score	22 (13)	29 (14)
Disease Duration (Years)	6.6 (5)	13.8 (10)

Table 2: Mean number of symptoms by NMS category PD vs YOPD

	PD	YOPD	Mann-Whitney U
Number of respondents	260	46	
Digestion (Max = 7)	2.5 (1.7)	2.8 (1.6)	U=5254.0, p=0.183
Urinary (Max = 2)	1.3 (0.8)	1.2 (0.7)	U=5738.0, p=0.636
Memory & Attention (Max = 3)	**1.5 (1.2)**	**1.9 (1.1)**	**U=4802.5, p=0.028**
Hallucinations & Delusions (Max = 2)	0.2 (0.5)	0.3 (0.5)	U=5430.0, p=0.118
Depression & Anxiety (Max = 2)	**0.9 (0.8)**	**1.2 (0.8)**	**U=4936.0, p=0.045**
Sexual Function (Max = 2)	0.9 (0.8)	0.9 (0.7)	U=5849.5, p=0.801
Cardiovascular (Max = 2)	**0.7 (0.8)**	**0.9 (0.7)**	**U=4797.5, p=0.020**
Sleep (Max = 5)	1.9 (1.3)	2.3 (1.5)	U=5101.0, p=0.103
Miscellaneous (Max = 5)	**1.4 (1.3)**	**1.8 (1.2)**	**U=4810.0, p=0.029**

Table 3: NMS breakdown individual items PD vs YOPD

	PD	YOPD	Chi-Square
Number of respondents	260	46	
Anxiety	42%	52%	χ^2=1.546 (1), p=0.140
Apathy	**44%**	**59%**	**χ^2=3.655 (1), p=0.040**
Bowel incontinence	10%	4%	χ^2=1.502 (1), p=0.173
Concentration problems	**56%**	**74%**	**χ^2=5.300 (1), p=0.015**
Constipation	42%	52%	χ^2=1.546 (1), p=0.140
Daytime sleepiness	27%	33%	χ^2=0.630 (1), p=0.266
Delusions	5%	13%	χ^2=3.753 (1), p=0.061
Dizziness	42%	52%	χ^2=1.546 (1), p=0.140
Double vision	18%	15%	χ^2=0.220 (1), p=0.410
Drooling	36%	33%	χ^2=0.171 (1), p=0.407
Excessive sweating	25%	44%	χ^2=6.333 (1), p=0.011
Falling	**25%**	**41%**	**χ^2=5.507 (1), p=0.017**
Forgetfulness	54%	61%	χ^2=0.865 (1), p=0.221
Frequent urination at night	64%	54%	χ^2=1.379 (1), p=0.156
Hallucinations	12%	15%	χ^2=0.298 (1), p=0.366
Incomplete bowel emptying	44%	48%	χ^2=0.251 (1), p=0.366
Insomnia	63%	74%	χ^2=2.146 (1), p=0.096
Pains	**49%**	**67%**	**χ^2=5.606 (1), p=0.013**
REM Behaviour Disorder	27%	28%	χ^2=0.059 (1), p=0.467
Restless Legs Syndrome	41%	54%	χ^2=2.774 (1), p=0.067
Taste and smell	46%	54%	χ^2=1.155 (1), p=0.180
Sadness	**51%**	**67%**	**χ^2=4.143 (1), p=0.029**
Sex drive changes	54%	67%	χ^2=3.072 (1), p=0.055
Sex difficulty	34%	22%	χ^2=2.632 (1), p=0.071
Swallowing	40%	50%	χ^2=1.485 (1), p=0.145
Swelling (Oedema)	28%	26%	χ^2=0.051 (1), p=0.489
Urinary urgency	63%	67%	χ^2=0.372 (1), p=0.332
Vivid dreams	36%	46%	χ^2=1.503 (1), p=0.145
Vomiting	28%	37%	χ^2=1.626 (1), p=0.136
Weight changes	20%	26%	χ^2=0.876 (1), p=0.226

Discussion

Using the NMS-Quest, we found that with YOPD (with an onset before 40 years of age) reported a higher prevalence of non-motor symptoms (a median difference of three more symptoms) than patients with the more typical form of PD.

Biological explanations

It has been suggested that YOPD patients are more likely to have an inherited form of PD and it is possible that some disease-causing mutations are more likely to be associated with non-motor symptoms than sporadic PD. Future research could combine genetic screening with non-motor symptom measures in YOPD.

Psychosocial explanations

Because YOPD patients were diagnosed in their mid-late 30's, it's possible that their non-motor symptoms were more noticeable (rather than more severe) than patients with the later onset of the disease. Patients in the YOPD group are more likely to have been working, driving, or looking after other family members such as young children or parents. By contrast the task demands on older patients might be lessened. Furthermore, many of the non-motor symptoms experienced in PD are also normal consequences of aging (e.g. constipation, difficulty concentrating, sexual difficulties) and so are perhaps less likely to be endorsed as a PD-related problem by older patients.

Methodological explanations

As our survey relied upon use of the Internet, it is possible that our sample is systematically biased in some way. However, the use of a comparison group recruited in the same way should mean that any biases affect both groups equally.

Finally, there may be some other unknown factor driving group differences, which we have not recorded. For the sake of brevity, we did not record co-morbidities or a complete medication list, for instance, and it may be that YOPD patients are more affected by psychiatric co-morbidities than older patients, or that they are more likely to be prescribed drugs with non-motor side effects. However, full utilization of the PatientsLikeMe treatment and symptom profile will allow further examination of this issue.

Conclusion

We recommend use of standardized measures like the NMS-Quest to ensure both motor and non-motor symptoms are addressed for patients with PD. Through the use of this measure, we have preliminary evidence that YOPD patients may have a different profile of disease burden. YOPD patients already struggle with having an unusual presentation of PD at an unexpected age; if they are also having to cope with a higher prevalence of non-motor symptoms we should ensure monitoring and management are increased too.

Future research should seek to highlight causes and potential treatments for non-motor symptoms, and patients should consider the use of tracking systems available via PatientsLikeMe to allow them to monitor their progression over time.

References

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