Patient perception of dyskinesia in Parkinson’s disease

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ABSTRACT
Objective To evaluate the perception of patients with Parkinson’s disease (PD) regarding dyskinesia.
Design Multicentre survey.
Setting Tertiary referral centres.
Patients Patients with PD participated in a survey: those not on dopaminergic medications (group I), those on dopaminergic medications without dyskinesia (group II) and those on dopaminergic medications with dyskinesia (group III).
Intervention After a short standardised description and explanation of dyskinesia was provided, patients were asked about the nature and source of prior knowledge of dyskinesia. They were then asked about their perceptions of dyskinesia. Patients in group III were also asked about the duration, the severity of dyskinesia and whether their perception of this problem had changed since its appearance.
Main outcome measures Level of concern regarding dyskinesia and whether their perception of dyskinesia would have changed their preference of treatment.
Results 259 PD patients completed the survey (group I, 52; group II, 102; group III, 105). Patients with dyskinesia were significantly less concerned about dyskinesia than patients without dyskinesia and were more likely to choose dyskinesia over being parkinsonian. Patients who required fewer changes in medications because of dyskinesia were more likely to choose dyskinesia over parkinsonism.
Conclusion Patients with PD experiencing dyskinesia are less likely to be concerned about dyskinesia and more likely to prefer dyskinesia over parkinsonian symptoms than patients without dyskinesia.

Concern about the development of dopaminergic drug-induced dyskinesia has greatly influenced clinical research studies and management decisions in Parkinson’s disease (PD) for more than two decades. Several studies have shown that initial therapy with a dopamine agonist, rather than L-dopa, results in a significantly lower incidence of dyskinesia.1 2 However, dopamine agonists may not provide an equivalent symptomatic response to that obtained from L-dopa, and certain side effects such as sedation and excessive daytime somnolence, leg oedema, hallucinations and impulse control disorders are all more common with agonists than levodopa.3–9

OBJECTIVES
To evaluate patients’ opinions and attitudes towards dyskinesia and whether and how they would like treatment decisions to be influenced by these concerns (“perception” of dyskinesia).

METHODS
English-speaking patients with PD10 were recruited between September 2003 and March 2006 from both the Movement Disorders Centre at the University of Toronto and the Neurology Clinic at the Medical College of Wisconsin.
Exclusion criteria included the presence of any other neurological disorder, intellectual impairment, significant depression and failure to distinguish the difference between dyskinesia and parkinsonian symptoms due to motor fluctuation despite explanation by the interviewer.
Surveys, Unified Parkinson’s Disease Rating Scale (UPDRS) scores and, where appropriate, the Lang–Fahn Activities of Daily Living Dyskinesia Scale11 were administered by movement disorders neurologists trained to conduct them in a standardised fashion.
The patients were first read a standard short passage with information about the cause and nature of dyskinesia (see online appendices for standard passage and surveys administered). Patients were divided into three groups: (1) patients not taking any dopaminergic medication, (2) patients on dopaminergic medication(s) but without dyskinesia and (3) patients on dopaminergic medication(s) with dyskinesia. Each group of patients was asked slightly different questions, but all were asked whether or not they had any prior knowledge of dyskinesia and its cause, how they perceived the importance of dyskinesia, and whether they would prefer dyskinesia or parkinsonian symptoms if they had to choose. Perception of dyskinesia was rated as 0 (“not concerned at all”) to 3 (“extremely concerned”). For group III, patients were also asked how many times their treatment had to be changed because of dyskinesia and whether they wished their initial treatment strategy had been different given what they knew currently. This information was checked against patients’ medical records at the two study sites to verify its accuracy when available.

STATISTICAL ANALYSIS
Group differences were evaluated. A series of analyses or variance followed by Bonferroni-adjusted pairwise comparisons were used to evaluate differences in current age, age of onset, age at diagnosis, follow-up duration, duration to treatment and UPDRS scores. Within each group, to evaluate whether prior awareness of dyskinesia was associated with patient concern about dyskinesia, a series of χ2/Fisher’s exact tests were performed. Among those with prior knowledge of dyskinesia, an additional series of Fisher’s exact tests and a Kruskal–Wallis test were performed to assess
whether the means by which they acquired knowledge of dyskinesia affected their degree of concern about dyskinesia.

In group III, a series of $\chi^2$ tests, Fisher’s exact tests and Mann–Whitney U tests were performed to study whether the number of previous changes to the patient’s medications because of dyskinesia changed their perception of dyskinesia. Bonferroni-adjusted pairwise comparisons were used to compare the Lang–Fahn Activities of Daily Living Dyskinesia Scale score and the level of concern.

To compare the degree of concern about dyskinesia among the groups, a series of $\chi^2$/Fisher’s exact (categorical), Kruskal–Wallis (quantitative) tests and Bonferroni-adjusted pairwise comparisons were performed.

A $p$ value of <0.05 was considered significant.

RESULTS

A total of 259 patients were enrolled. Table 1 lists all patient characteristics including the main sources of information on dyskinesia.

All groups

The degree of concern with regard to dyskinesia (0–3) differed significantly across the three groups: group I and II were highest (mean 1.63 (0.79) and 1.22 (0.86)), and group III was the lowest (mean 0.86 (0.75)). Groups I and II (without dyskinesia) did not differ significantly from one another (adjusted $p=0.13$); both demonstrated significantly greater concern than group III (existing dyskinesia) (adjusted $p<0.01$). In groups I and II, slightly more than half indicated that they would rather tolerate worsened parkinsonian symptoms (group I 53%, group II 51%) than have dyskinesia, whereas in group III, 83% chose to tolerate dyskinesia (adjusted $p<0.01$ for comparisons between groups I and III and groups II and III). The difference between groups I and II was not significant (figure 1).

Group III (with dyskinesia)

The severity of the Lang–Fahn Activities of Daily Living Dyskinesia Scale score correlated with concern about their current level of dyskinesia ($r=0.56$, $p<0.0001$), but it did not have any significant influence on their concern regarding treatment choices at the time of commencement of treatment ($r=0.10$, $p=0.3$). Overall, most patients preferred to tolerate dyskinesia (83%) rather than worsening of their parkinsonian symptoms (17%). This result was still evident but less pronounced among those who had required changes to their medications because of dyskinesia; these patients expressed significantly higher concern about dyskinesia than those who had not required any changes to their medication regimen ($p<0.01$) (figure 1). The number of medication changes did not influence the degree of concern.

In patients who knew about dyskinesia before their onset, when asked how the severity of dyskinesia compared with what they expected before experiencing them, 28% reported that their dyskinesia were on par with their expectations, 47% thought their dyskinesia were worse than expected and 25% felt they were worse than expected.

DISCUSSION

The results of this survey confirm what many movement disorders neurologists have observed in their clinical practice but has never been proven by a systematic study, that most patients

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**Table 1** Patient characteristics and comparison of prior knowledge of dyskinesia

<table>
<thead>
<tr>
<th></th>
<th>Group I (untreated)</th>
<th>Group II (treated; without dyskinesia)</th>
<th>Group III (treated; with dyskinesia)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of patients</td>
<td>52</td>
<td>102</td>
<td>105</td>
</tr>
<tr>
<td>Number of males (%)</td>
<td>33 (63.5)</td>
<td>53 (52.0)</td>
<td>71 (67.6)†</td>
</tr>
<tr>
<td>Current age (years) SD)</td>
<td>62.4 (12.6)</td>
<td>65.4 (10.6)</td>
<td>64.1 (9.3)†</td>
</tr>
<tr>
<td>Age at diagnosis (mean SD))</td>
<td>60.4 (12.8)</td>
<td>60.5 (11.6)</td>
<td>53.8 (9.7)‡</td>
</tr>
<tr>
<td>Time followed in clinic (months)</td>
<td>5.0 (112)</td>
<td>30.5 (0, 155)</td>
<td>70.0 (0, 233)§</td>
</tr>
<tr>
<td>Time from diagnosis to starting dopaminergic agent (months)</td>
<td>Not applicable</td>
<td>2.0 (0, 120)</td>
<td>0.0 (0, 12)¶</td>
</tr>
<tr>
<td>UPDRS III score mean (SD)</td>
<td>19.7 (9.7)</td>
<td>21.9 (9.5)</td>
<td>24.8 (12.1)**</td>
</tr>
<tr>
<td>UPDRS Q32 mean (SD)</td>
<td>0</td>
<td>0</td>
<td>1.5 (0.96)</td>
</tr>
<tr>
<td>UPDRS Q33 mean (SD)</td>
<td>0</td>
<td>0</td>
<td>1.0 (0.92)</td>
</tr>
<tr>
<td>Lang–Fahn Dyskinesia Scale score (mean maximum score=20) (mean SD))</td>
<td>0</td>
<td>5.6 (4.9)</td>
<td></td>
</tr>
</tbody>
</table>
| Source of information about dyskinesia if patient was aware of dyskinesia before survey (or, in group III, before developing dyskinesia) | Medical sources n=7 (30%), media n=8 (34%), other patients n=5 (25%); multiple sources n=8 (25%) | Medical sources n=18 (26%), media n=21 (31%), other patients n=8 (12%), multiple sources n=20 (30%) | Medical sources n=17 (37%), media n=12 (27%), other patients n=3 (7%), multiple sources n=14 (20%)
| Aware of the phenomenon of dyskinesia before the survey (or, in group III, before developing dyskinesia) (% of total) | Yes n=24 (46%), no n=28 (54%) | Yes n=68 (67%), no n=34 (33%) | Yes n=46 (44%), no n=59 (56%)
| Aware that dyskinesia is related to treatment with levodopa and other dopaminergic agents? (% of total) | Yes n=20 (38%), no n=32 (62%) | Yes n=38 (37%), no n=84 (63%) | Yes n=33 (31%), no n=72 (69%)
| Current dopaminergic medications (n) | None | l-dopa 87, DA 43, COMT-I 1 | l-dopa 105, DA 74, COMT-I 19 |
| MAOB-I 11, amantadine 7 | MAOB-I 10, amantadine 41 |
with PD who have experienced dyskinesia, when given a choice between being parkinsonian or having less parkinsonian symptoms, but at the expense of having dyskinesia, choose the latter. In the groups of patients without dyskinesia (groups I and II), the choice was more evenly distributed between dyskinesia and parkinsonism. Not surprisingly, the level of concern regarding dyskinesia also tended towards “not concerned” and “mildly concerned” in the group of patients with first-hand experience with dyskinesia compared to patients without dyskinesia. The effect of dyskinesia on quality of life has been controversial. In a recent study from the Mayo Clinic, although dyskinesia was increasingly common over ≥5 years of L-dopa treatment, cases of dyskinesia severe enough to require medication adjustments and especially cases of dyskinesia resistant to medication adjustments were uncommon. The results of the current survey, that patients with more advanced disease, despite having greater problems with quality of life, would choose dyskinesia over parkinsonism suggest that, for most patients, dyskinesia may play a less important role in the determination of quality of life compared to other factors such as progression of disease and motor fluctuations.

The predominant current treatment strategy of delaying L-dopa treatment by using dopamine agonists instead, at the possible cost of reduced efficacy and an arguably worse side effect profile, is based largely on the assumption that dyskinesia is undesirable and likely disabling. However, there is little evidence that the delay in dyskinesia with initial agonist treatment translates into a long-term advantage of improved quality of life. The current survey does not diminish the urgency of developing more effective and safer therapies; however, until better solutions are available, our results emphasise that a concern about the future development of dyskinesia, which often drives a form of “L-dopa phobia”, should not compromise optimal control of parkinsonism.

There are limitations to our study. Ideally, a longitudinal study would be more accurate in exploring changes in patient perception of disease progression, but it would be difficult and expensive. For practical purposes, UPDRS motor scores were obtained at routine clinic visits rather than in defined off states, which would have better reflected the severity of the disease in the treated patients. Although there may have been poorly understood cultural, educational, economical and social factors that could have influenced the results of the survey, patients were recruited prospectively mainly from one large metropolitan movement disorders clinic in Canada that services a multicultural population in a socialised healthcare system. Overall, patients in group III had mild to moderate dyskinesia. However, we did not preselect or exclude patients with more severe forms of dyskinesia who might have been more concerned about this side effect. Our sample is representative of patients attending a subspecialty movement disorders clinic, which probably represents a population with more severe motor complications than a community-based sample.

We have shown that patients with first-hand experience of dyskinesia are less likely to be concerned about the side effect and are more likely to prefer dyskinesia over increased symptoms of parkinsonism. Because quality of life may be more dependent on the severity of parkinsonism and less on the presence of dyskinesia, this observation should be taken into account by prescribers and patients in making an informed decision regarding initial treatment strategies in PD.

> **Figure 1** (A) PD patients without current dyskinesia (groups I and II) would prefer to tolerate parkinsonism than dyskinesia; PD patients with current dyskinesia preferred to have dyskinesia than parkinsonism. Within group III, there is a significant difference in preference between patients who have had medication changes because of dyskinesia and those who did not. Figure showing patient preference of dyskinesia or parkinsonism in the three groups of patients. See legend for table 1. The distribution is significantly different between groups I and III, and between groups II and III (p<0.01). There is no significant difference between groups I and II. Among group III patients, those who did not have to change medication because of dyskinesia are more likely to prefer dyskinesia to parkinsonism (p<0.05). (B) PD patients without dyskinesia (groups I and II) were more concerned about dyskinesia than PD patients with dyskinesia (group III). In B, the level of concern about dyskinesia was shown among the three groups of patients rated using the scale as described in the text (see legend for table 1). The distribution is significantly different between groups I and II, and between groups II and III (p<0.01). There is no significant difference between groups I and II (NS). PD, Parkinson’s disease.

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**Competing interests** None.

**Ethics approval** This study was conducted with the approval of the institutional review boards of the University of Toronto and the Medical College of Wisconsin.

**Contributors** Study concept and design: AEL, SWH. Acquisition of data: SWH, GMA, SHF. Analysis and interpretation of data: TA, SWH, AEL. Drafting of the manuscript: SWH, SHF, AEL. Critical revision of the manuscript for important intellectual content: SWH, SHF, AEL, GMA, TA. Statistical analysis: TA.

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**REFERENCES**

Jerky movements from levodopa often not as bad as Parkinson's patients expect

Many people with Parkinson's disease delay starting treatment with levodopa, because they're worried about the jerky movements (dyskinesia) that this drug can cause with long-term use. However, a new study suggests that many people who take levodopa actually prefer their dyskinesia to the Parkinson's symptoms they would get if they didn't take the drug. This suggests that earlier levodopa treatment may be preferable for some patients.

What do we know already?

Parkinson's disease affects how you move. An early sign is a slight trembling in one hand. Over time, you start doing things more and more slowly as your muscles become stiff. You may lose your balance more easily.

Treating Parkinson's disease is complicated. Levodopa is the main drug for the disease, and can work well at first. You may even forget you have Parkinson's when you start taking it. But after taking levodopa for two to five years, you may get problems from the drug, including dyskinesia. These involuntary movements can happen just before or after you take your dose of levodopa, or midway between two doses. You may nod your head over and over again. Or you may jerk your leg, smack your lips, or make a strange face.

Concern over dyskinesia often influences when people start taking levodopa. Many patients opt first to take drugs called dopamine agonists. However, these drugs don't work as well as levodopa and also cause their own side effects, including sleepiness, leg swelling (oedema), and hallucinations.

So what's the best approach for most people? There's debate about this, as it's unclear how severely dyskinesia affects people's quality of life, compared with the problems they would get from Parkinson's if they weren't taking the drug.

Researchers have now done a study to find out whether concerns over dyskinesia are borne out once people develop these movement problems. The study included 259 people with Parkinson's. Some were not taking levodopa, others were taking the drug but did not yet have dyskinesia, and others had developed dyskinesia.
The researchers asked participants about their prior knowledge of dyskinesia and their perceptions of these movement problems. People with dyskinesia were also asked whether their perceptions had changed once they started getting these involuntary movements.

**What does the new study say?**
People who didn't yet take levodopa or had not yet got dyskinesia from the drug were much more concerned about these movement problems than people who had them. Slightly more than half said they would rather tolerate worsened Parkinson's symptoms than have dyskinesia. In contrast, 83 percent of people with dyskinesia preferred these movement problems to their Parkinson's symptoms. Among people with dyskinesia, 47 percent said these involuntary movements were not as bad as they'd expected, 28 percent said they were on par with their expectations, and 25 percent said they were worse than they expected.

**How reliable are the findings?**
This was a well-designed study that provides valuable insight into perceptions of dyskinesia among Parkinson's patients, both before and after the onset of these problems. However, the study would have been even stronger if it had followed patients over several years and assessed their changing perceptions over time.

**Where does the study come from?**
The study was done by Canadian and US researchers based in Toronto and Milwaukee, Wisconsin. Most of the participants were recruited from a large movement disorders clinic in Canada.

**What does this mean for me?**
Deciding when to start levodopa treatment can be difficult. There are many variables to consider, including your age, the severity of your symptoms, and how the disease is affecting your life. You may also be concerned about the drug's side effects, and that it may not work so well with long-term use. If one of your chief concerns is getting dyskinesia, this study shows that these movement problems often aren't as bad as people expect and that many people would choose this side effect over their Parkinson's symptoms. This suggests, say the researchers, that dyskinesia may play a less important role in shaping a person's quality of life than other factors relating to their Parkinson's disease. As a result, earlier levodopa treatment may be a good option for some people.
What should I do now?

If you and your doctor are weighing up the benefits and risks of starting levodopa treatment, you might mention this study as part of your discussion. Your doctor can help put its findings into perspective for you. It might help to talk to someone who has been in the same position. You could contact the Parkinson’s Disease Society (http://www.parkinsons.org.uk) for advice.


This summary was prepared by the staff of Best Health, BMJ Group’s patient information service. This information does not replace medical advice. If you have a medical problem please see your doctor.