Information for patients from JNNP

Do patients’ ratings of Parkinson’s symptoms match symptom scores?

Introduction
Asking people with Parkinson’s disease to rate how much their symptoms have improved doesn’t seem to match up to improvements as measured by conventional symptoms scores used by doctors and researchers.

What do we know already?
Doctors and researchers use different symptom scores to help measure the symptoms of people with Parkinson’s disease. Examples are the Unified Parkinson’s Disease Rating Scale (UPDRS), the Mini-Mental State Examination (MMSE), and the 39-item Parkinson’s Disease Questionnaire (PDQ-39).
These tools are useful as they allow doctors to assess how much a person is affected by the symptoms of Parkinson’s. They also use these scores to weigh up if a treatment works, by measuring the patient’s symptom scores before and after treatment. The scores can be important for working out if a person has Parkinson’s disease, or a different type of movement disorder. People with Parkinson’s will usually improve after taking drugs called dopamine agonists. After taking dopamine agonists, people with Parkinson’s disease should be able to control their movements better. However, dopamine agonists don’t work for people with other movement disorders.
In addition to symptom scores, doctors will often ask people how they feel after taking treatment. It can be useful for people to assess for themselves if their symptoms have improved, and to try and say how much they feel they have improved.
This study of 133 patients with Parkinson’s disease measured the improvement in people’s symptoms immediately after starting treatment with dopamine agonists, then again after an average of six and then 12 months of treatments.
Researchers used symptom scores and tests, as well as asking people to rate how much their symptoms had improved. They then compared the test results with people’s own ratings, to see how they matched up.
What does the new study say?

Most patients showed improvements in their measured scores but there was little relationship between these scores and how patients rated their own symptoms.
The best match was between people’s scores and the results of the UPRDS. When the researchers compared people’s own scores with this scale, they found around 33 in 100 people who showed no improvement in their UPDRS score at the first follow-up rated their improvement as moderate or better. Around 29 in 100 of those whose UPDRS score showed a good response said they had either no improvement or only a slight improvement.

How reliable are the findings?

This is a small study and the researchers say they would need more people to be confident that the results are not due to chance. The researchers didn’t use the same symptom score at every follow-up appointment. These scores are designed to measure slightly different things, so this might have affected the scores and made the results less reliable. Also, it’s possible that the differences in symptoms – and whether or not they were accurately measured by the scores – were affected by the natural progression of people’s Parkinson’s disease. The researchers were not able to rule this out and so we don’t know if it affected the results. People may also not have been able to remember what their symptoms were like earlier, and so may not be sure how much their symptoms had improved.

What does this mean for me?

The researchers say that their results suggest doctors and people with Parkinson’s disease don’t always have the right information to make decisions about which treatments to use. It may also mean people are wrongly told which movement disorder they have. So, to be sure, doctors and people with Parkinson’s disease shouldn’t rely only on their own ratings of their symptoms, or on symptom scores, but use both in a way that complement each other.