

Quality of Life for Patients With Parkinson Disease

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Related Article

Association of Motor and Nonmotor Symptoms With Health-Related Quality of Life in a Large Online Cohort of People With Parkinson Disease

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Researchers have been studying an idea called health-related quality of life (HRQOL) for many years. What is HRQOL? In 1998, Dr. Martinez-Martin gave this definition: a “patient’s own perception and self-evaluation regarding the effects of an illness and its consequences on her or his life.”¹ Doctors often try to grade how severe the symptoms of a disease are when they examine a patient. But this leaves out all the symptoms a person has that a doctor cannot see. This is especially true for patients with Parkinson disease (PD). HRQOL may be a way of looking at how all symptoms of a disease, both the visible and invisible, are affecting a person. The authors of this study wanted to find out which PD symptoms or details about a person affect quality of life for people with PD.²

How Was This Study Done?

The authors used data from the Fox Insight Study to answer this question. Fox Insight tries to learn about people’s experiences with PD by having them fill out surveys online. Survey responses from 23,058 participants were used for this study. Participants shared basic information about themselves such as their age, how many years of school they completed, and how much money they make. They also gave information about their PD symptoms and whether they had any other medical problems. The authors then looked at each participant’s responses to find out whether each item affected quality of life. They also divided nonmotor symptoms (such as sleep problems, digestive problems, and mental health problems) into groups to look at whether certain types of symptoms affect quality of life more than others.

What Were the Main Findings?

In general, the authors found that the participants in the study reported a relatively high HRQOL. The participants with worse depression, more severe motor symptoms, or who had other medical problems in addition to PD reported a lower quality of life. Having more motor symptoms worsened quality of life more for certain participants, including women, those with a lower level of education or income, those with more severe depression, and those who

had more difficulty with thinking (also called cognition). Individuals who experienced falls had a lower quality of life. The researchers also found nonmotor symptoms were very common. Sleep, gastrointestinal, and mental health symptoms were especially common. More than 80% of the participants experienced at least 1 of these symptoms. Of these, mental health symptoms worsened a person's quality of life the most. These symptoms included things like loss of interest, sadness/low mood, trouble concentrating, and anxiety.

What Does This Mean for Patients With PD?

Each person with PD may have a different view of his or her own quality of life and different factors may affect that view. This research study looked at a large group of patients with PD to determine which factors that are related either to the disease or to the individual person have the greatest effect on quality of

life. If doctors or researchers know which factors are most important to patients, they can try to find ways to treat them more effectively. For example, this study suggests that depression greatly affects a person's quality of life and that having more severe depression may increase the negative effect of motor symptoms in PD. Depression can and should be treated and more studies are needed to help clarify which antidepressants work best for people with PD. Not only is it important for patients to talk to their doctors about all the symptoms they feel are affecting their life, doctors should also ask patients about these symptoms.

What Is Next?

More studies are needed to see how quality of life changes over time in PD. Even though this study looked at a large number of people, it may have left out certain groups of people. It will be important to study those groups in the future.

About Parkinson Disease

What Is Parkinson Disease?

Parkinson disease (PD) is caused by the gradual loss of a substance in the body called dopamine. Dopamine is made in a part of the brain called the basal ganglia. Even though PD is a disease of the brain, many other parts of the body can be affected. People with PD have different sets of symptoms.

Who Is Affected by PD?

The number of people diagnosed with PD is increasing rapidly.³ This may be because more people know about the disease now or because people are living longer on average. The risk of developing PD increases as a person ages, so people who are 85–89 years old are at the highest risk.³ Men are 1.4 times more likely to develop PD than women.³

What Causes PD?

For most people with PD, it is unclear what caused their disease. Sometimes PD is passed down in families, but this is uncommon. Environmental factors, such as exposure to certain pesticides, may increase a person's risk of developing PD.

What Are the Symptoms of PD?

Symptoms of PD can be separated into 2 groups: motor symptoms and nonmotor symptoms. Motor symptoms are the physical symptoms of PD that can be seen by others. These include tremor (shaking), slow movements, stiffness, and balance difficulties. There are also many nonmotor symptoms in PD. People with PD may find it difficult to have bowel movements, control their urination, or have sex. They may develop problems with thinking or have changes in their behavior. They can also have trouble sleeping or have rapid changes in their blood pressure.

How Is PD Diagnosed?

The diagnosis of PD can be given when a doctor finds certain clues on a person's examination report. There are no blood tests or scans that confirm the diagnosis. An MRI is not typically useful in making the diagnosis of PD. At times, a test called a DaTscan is used to rule out other diseases. This is only used if the diagnosis of PD is not clear from the examination.

How Is PD Treated?

There is no cure for PD and treatment is used to help manage the symptoms. There are many medications that help decrease the symptoms of PD. Often, these are focused on boosting dopamine levels in the brain. Levodopa is the most common medication used to treat the motor symptoms of PD, but there are many others.⁴ Each person with PD is different and should work with the doctor to find the right set of medications for them. There are also several brain surgeries that can help with the symptoms of PD. Deep brain stimulation surgery is one example. Exercise is the only tool that may keep PD symptoms from getting worse. It can be helpful for patients with PD to work with physical therapists, occupational therapists, and speech therapists. Patients with PD often do best when they work with a team.

For More Information

Brain & Life

brainandlife.org

American Parkinson Disease Association

apdaparkinson.org

Michael J. Fox Foundation

michaeljfox.org

Parkinson's Resource Organization

parkinsonsresource.org

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