

Report says Parkinson's disease diagnoses must include a message of hope

December 21 2023



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As Parkinson's disease diagnoses continue to rise in the U.S., limited patient access to movement disorder specialists means the job of delivering the often-devastating, life-changing news falls on primary care

physicians or community neurologists who may not have the necessary expertise for this sensitive task.

A new [report](#) by a UCLA neurologist and collaborators draws upon patient voices and lived experiences to identify the common pitfalls of Parkinson's [diagnoses](#) and create a guidebook for how medical providers—from seasoned specialists to rural community physicians—can avoid them.

"I think there is a lot of mythology around the disease," said UCLA Health movement disorders neurologist Dr. Indu Subramanian, who is lead author of the report published in the journal *Parkinsonism and Related Disorders* this month. "A lot of people say 'I'm sorry, you have Parkinson's.' In fact, I think it's a very treatable disorder. Giving hope, giving the patient agency is a critical part of the message.

"So instead, the doctor should say 'You have Parkinson's and these are the things that you can do to live better and here are some people who can support you and I'm part of your team,'" Subramanian continued.

About 90,000 people are diagnosed with Parkinson's disease each year in the U.S., which has doubled from the previous estimate in 2012 of 40,000-60,000 diagnoses, according to a 2022 study funded by the Parkinson's Foundation nonprofit group. The study states the reason for the greater incidence in diagnoses remains unexplained.

About 1 million people in the U.S. live with Parkinson's disease with the number estimated to increase to 1.2 million by 2030, according to the Parkinson's Foundation. There is no known cure for the disease.

How a diagnosis is delivered and the words that are used can impact a patient for years, with some patients falling into long periods of demoralization and hopelessness, Subramanian said. The report notes

that similar to dementia, there is an increased risk of suicide within 180 days of a Parkinson's disease diagnosis.

While past studies and methods have been developed for delivering bad news as it relates to cancer or dementia diagnoses, Subramanian said such guidance hadn't been well curated for Parkinson's disease.

"I have a number patients who have told me about things that have adversely affected them and it became clear that the way that the diagnosis of Parkinson's is given is something that is not done well. A lot of patients have especially hung their hat on that diagnosis day—some refer to as 'D Day'—they remember it very clearly," Subramanian said. "Meanwhile I think there is a growing body of people—women, [young people](#) with Parkinson's, minoritized populations—who talk about how sometimes their diagnosis was missed and they didn't get the care that an older white man would get."

The report makes a number of recommendations. Doctors should deliver the diagnosis in person and use correct terminology, avoiding euphemisms such as "honeymoon phase" to describe the initial period of the diagnosis.

Additionally, it lists recommendations for doctors from report co-authors who live with Parkinson's disease as well past patient surveys. These recommendations include having doctors provide guidance and education for how they should care for themselves; new treatment options; [coping strategies](#); and what lifestyle choices they should incorporate from diagnosis. Doctors may also wish to spread the news of the diagnoses over two appointments, recommending that the patient also bring in a family member or trusted friend to their second appointment if they came along to the first appointment.

"I think that is pretty exciting to have a team of physicians from around

the world explore together how we can do better and are humble enough to learn from and include the people we're serving," Subramanian said. "I hope this paper starts to create a dialogue and some much-needed change."

More information: Indu Subramanian et al, Delivering the diagnosis of Parkinson's disease- setting the stage with hope and compassion, *Parkinsonism & Related Disorders* (2023). DOI: [10.1016/j.parkreldis.2023.105926](https://doi.org/10.1016/j.parkreldis.2023.105926)

Provided by University of California, Los Angeles

Citation: Report says Parkinson's disease diagnoses must include a message of hope (2023, December 21) retrieved 8 May 2024 from <https://medicalxpress.com/news/2023-12-parkinson-disease-message.html>

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