

Doctors treating patients with Parkinson's disease must focus on stigma, emotional impacts as well as motor symptoms

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Even the best treatment approaches for Parkinson's disease are inadequate if they do not address patients' feelings of social rejection,

isolation, loneliness and other psychosocial effects of stigma, according to a report from experts specializing in Parkinson's and other movement disorders.

A new report co-authored by UCLA Health neurologist and researcher Dr. Indu Subramanian says many misconceptions and biases cause patients with Parkinson's to be stereotyped, devalued and shunned, which along with a progressive loss of functionality and independence, often lead to "self-stigma," with declining self-esteem and increasing anxiety and depression. The report appears in *Parkinsonism & Related Disorders*.

"Although the [motor symptoms](#) and limitations of Parkinson's disease must be a major focus of diagnosis and treatment, if we target only neurological dysfunction without also pursuing causes and effects of mood disturbance, we will be doing a major disservice to our patients," said Subramanian. "Stigma is not merely a minor inconvenience associated with this disease. It significantly contributes to quality of life."

Parkinson's disease, a progressive brain disorder, causes wide-ranging symptoms; some are not visible but others eventually can't be concealed. These may include tremor, involuntary movements, difficulty with balance, stooped posture, drooling, and "facial masking"—a loss of muscle control that results in an inability to properly show facial expressions.

"Any [chronic illness](#) can result in changes in physical appearance and bodily function, distorting not only a person's self-concept, but also how the person is perceived by others. People often make judgments about those with Parkinson's disease, particularly if they have visible symptoms like stooped posture, gait abnormalities, facial masking and tremor. These perceptions of 'disability' perpetuate [negative stereotypes](#)

and subsequent social devaluation," said Subramanian, who has written extensively about the disease, with recent articles on meeting the [unique needs of female patients](#) and making dietary and other [practical treatment decisions to optimize patient care](#).

Subramanian and colleagues say stigma is known to negatively impact quality of life for patients with Parkinson's, but there has been little research devoted to the subject. The new article reviews findings from previous studies on stigma, [social isolation](#), stress, shame and other related factors before focusing on how doctors, medical teams, patients and supporters can work together to manage the effects of stigma.

Awareness is a start, and [health care professionals](#) need to develop a tool to routinely assess stigma and identify its effects on patients. "And if not physician-initiated, patients must feel empowered enough to bring these issues to the attention of their medical team," the authors said.

Subramanian and colleagues emphasized the need for:

- Patient empowerment through individual counseling and focus, "with interventions directed at knowledge, self-concept, self-esteem, and developing coping skills."
- Support groups to improve [self-esteem](#) and coping skills and lessen isolation.
- Education, including "providing the general public with accurate information about the illness, the lived experience and countering false assumptions upon which stigma is based."
- Formal interventions using therapies that identify and address the numerous factors that can result from stigma.

"Parkinson's disease results in an illness burden that includes both visible and invisible symptoms. The resulting stigma can lead to social anxiety and isolation, reluctance to seek medical care, loneliness, depression and

anxiety," the authors write. "Having a better understanding of the role of stigma and its impact may allow clinicians to provide proactive care and greater empathy for those living with the challenges of this disease."

Subramanian is senior author. Bradley McDaniels, Ph.D., of the University of North Texas, is first and corresponding author. Other authors include Dr. Gregory Pontone, of Johns Hopkins School of Medicine, and Dr. Soania Mathur, of Unshakable MD in Toronto, Canada.

More information: Bradley McDaniels et al, Staying hidden: The burden of stigma in PD, *Parkinsonism & Related Disorders* (2023). [DOI: 10.1016/j.parkreldis.2023.105838](https://doi.org/10.1016/j.parkreldis.2023.105838)

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