



Comments

Stigma in Parkinson's disease: Placing it outside the body



Stigma in Parkinson's disease

Parkinson's Disease (PD) has traditionally been characterized by its motor symptoms (e.g., bradykinesia, rigidity, and tremor),¹ however the disease burden also comprises other non-motor symptoms² and psychosocial problems that can negatively impact patients Health-Related Quality of Life.³ A significant one is a stigma which both PD and caregivers experience due to their condition. Stigma could be defined as an attribute implying a discredit of the individual who is considered "bad, weak or dangerous", reducing it to a representation from a whole and usual person to a tainted one.⁴ As a matter, more than 50% of patients with PD conceal their diagnosis,⁵ trying to mask some of their clinical symptoms^[6] or even avoid appearing in public.⁷ This stigma emanates from the interplay between patient and environment, where stigmas place the burden on the stigmatized subject.^{8,9} Like any other neuropsychiatric disease, PD is a categorization tool used by physicians and researchers for a better understanding of this phenomenon and the development of effective therapies and care. However, this tool is embedded in social, cultural, and political dimensions, which directly affect the construction of stigma against these populations. Efforts are made by researchers and clinicians in order to minimize the effect stigma has on patient wellbeing and quality of life, often analyzing how some disease characteristics like severity of motor symptoms or emotional disorders affect this situation. Despite the direct relation patient functional and bodily states may have with stigma, the authors should consider this socio-cultural component intrinsic to this phenomenon in order to accurately approach a solution.

Clinical symptoms observed in PD patients can lead to communicative and social disruptions,¹⁰ especially those symptoms related to emotion expression and recognition like facial masking, constituting what has been named as 'social symptoms of PD',¹¹ which largely contribute to stigma experience. In this line, clinical research has also explored how stigma could be predicted from disease characteristics like depression,^{12,13} low scores in Activities of Daily Living (ADL),^{12,14} or severe motor symptoms.^{13,15} These associations between clinical symptoms and stigma are usually followed by the logical conclusion that ameliorating those symptoms is the path to take to effectively reduce stigma in PD patients, further suggesting the collection of more biomedical variables with the potential to emerge as predictors of stigma. Besides the evident impact motor symptoms improvement could have on experienced stigma in PD patients, studying stigma solely through the analysis of symptoms and functional capacities of patients places the burden of stigma on the bodies of patients, largely neglecting the socio-cultural dimension intrinsic to stigma phenomenon.⁸ Authors are often aware of this conflict, as they state the importance of this socio-cultural dimension, while at the same time, the variables explored relate almost exclusively to patients' bodies, and the socio-cultural aspect remains

unexplored. Despite the focus on clinical symptoms associated with stigma in PD, these studies also reported differences in the few social variables they collected like gender^[13] or age,^{13,14} reinforcing the standpoint of stigma as socio-cultural informed. Results also showed how emotional disorders were robust predictors of stigma,^{12,13} which are largely affected by social discrimination.¹⁶

This gap between the socio-cultural dimension of stigma and the bodily states of patients reflects the relation between epistemology and ontology within biomedical research and practice, showing how the production of knowledge could be influenced by socio-cultural contexts. Therefore, the authors need approaches that tackle this complexity, further exploring this aspect of stigma. The review of Maffoni et al.¹⁷ try to describe a new understanding of stigma from an intercultural and social viewpoint, moving to a patient-centered approach that contextualizes clinical symptoms within a broader dimension of socio-cultural interactions. This kind of understanding of stigma in PD is present in other studies,¹¹ where authors also stress the importance of properly identifying stigma when it is invisible to physicians.⁶ Henry et al.¹⁸ reported differences in stigma between Mexico and USA patients and caregivers, showing potential cultural differences of stigma. The authors share with these authors the notion of stigma as a subjective symptom, which, besides its relationship with clinical symptoms, emerges mainly from the interaction between individuals and society as a whole.

Clinicians and researchers are also social actors embedded in socio-cultural environments regarding the biomedical care they deliver. In addition to the treatment of motor and non-motor symptoms, which largely impact patients' wellbeing, they could also address the social and political dimensions encompassing diseases like PD, aiming to alter current understandings and create responses from a clearer view of patient's experiences.¹⁹ If stigma is fundamentally a social-based issue, why put the focus on biomedical variables regarding the patients' body, when it would be more relevant to explore factors in direct association with social discrimination and stigma like socioeconomic status, prior experience of trauma, accessibility to healthcare specialists or access to caregiving.²⁰ This way, the authors would be placing the burden of the stigma where it belongs, outside patients' bodies, both in clinical practice and in research.

Conflicts of interest

The authors declare no conflicts of interest.

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