

Neuropsychiatric Symptoms and Caregiver Burden in Parkinson's Disease: Mitigating the Lack of Awareness!

With all its motor and nonmotor symptoms, Parkinson's disease (PD) is quite challenging to deal with, for patients and their caregivers alike. Caregivers help PD patients deal with their symptoms even before a formal diagnosis is made. They support their ailing family member while going through the tedious process of diagnosis, treatment to palliative care. These everyday challenges faced by the care partners affect their emotional, social, financial, physical, and spiritual functioning, and the extent to which they perceive this effect can be operationalized as a caregiver burden.^[1]

PD commonly affects patients in the age when they are transitioning to retirement. This subjects their caregiver to the stress of adapting to a new role and multiple lifestyle changes. Persons with PD, in addition to problematic motor symptoms, may develop nonmotor symptoms like apathy, depression, anxiety, impulse control disorders, psychotic symptoms, dementia, hearing problems, and sleep disorders. All of these symptoms further amplify the caregiver burden. Furthermore, advanced treatments like deep brain stimulation hardly improve this burden and might even make it worse, given their behavioral adverse effects of impulsivity and compulsivity.^[2] Improving this burden may reduce the risk of caregiver burnout, prevent premature institutionalization, and reduce morbidity.

Evidence for this caregiver burden comes exclusively from high-income countries, and the assumption that necessities of PD patients and the caregiver needs in low to middle-income countries (LMIC) are similar to those in high-income countries, clearly ignores many added challenges associated with providing care in LMIC. Caregivers in LMIC face societal challenges such as insufficient medical, educational as well as social services. Health care spending in these countries is often limited, not to mention the shortage of health care workers.^[3] With these limited resources of low-income countries, it is often challenging to liaison with a social worker or a psychiatrist to address the specific caregiver issues. Hence, more often than not, problems faced by caregivers remain unaddressed during routine clinic visits.

Paper titled "Neuropsychiatric symptoms and caregiver burden in Parkinson's disease," highlight critical, although often neglected,^[4] topic of adversities faced by caregivers of a person with PD. Authors show that the neuropsychiatric symptoms (NPS) like anxiety, apathy, irritability, agitation, and sleep problems correlate with the caregiver burden assessed by Zarit Caregiver Burden Inventory (ZBI). Although not assessed in the present study, caregivers experience a significantly higher burden while caring for PD patients with dementia and NPS.^[5] These NPS are more frequent as PD patients invariably

enter advanced disease stages, and expectedly, authors have observed a positive correlation between these advanced H and Y stages ($R^2 = 0.53$) and ZBI scores.

A lack of understanding about the nature of these NPS may make caregivers see the person they care for as unwilling to help themselves, which might result in a significant strain on their relationship.^[6] In a recent study, Lee *et al.* investigated this very problem and observed a positive association between the increased burden of care and low understanding of the disease by the caregiver.^[7] This was again especially vital in caregiving spouses, who accounted for 76% of the care providers in the present study. This lack of awareness might even be more prevalent in LMIC but has not been adequately studied. It is important to note that in the present study, caregiver burden was found to be unrelated to their educational level ($R^2 = 0.02$). This should not drive the reader away from the underlying problem of lack of awareness, since higher educational level may not necessarily indicate a better understanding of the disease. In fact, this may point towards a need for disease-specific education across all levels of education classes.

Lack of awareness can be alleviated by increasing the involvement of Parkinson's support groups and non-profit organizations, where caregivers can share their experiences and also learn more about the disease. Study assessing the utility of these patient education programs for PD and caregivers showed a significant improvement in patients' quality of life (QoL) as well as a significant reduction of caregivers' psychosocial burden and need for help.^[8] Similar results are seen in caregivers to patients who have dementia.^[3,9]

In conclusion, our efforts to address these NPS should go beyond the medical treatment of behavioral disturbances in PD patients. Early psychotherapeutic targeting of dyads with poor relationship quality at baseline, along with increased liaison with non-profit organizations, might be an useful alternative to consider, especially in resource-limited settings. We must build the necessary evidence through longitudinal as well as targeted studies to identify and address factors necessary to improve disease-related understanding in caregivers. Devising a systematic educational program for patients and caregivers in LMIC will pave the way forward towards a more holistic patient and caregiver management and will undoubtedly mitigate this burdensome caregiving.

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