

Caregiver Burden in Parkinson's Disease Patients Post-Deep Brain Stimulation: A Neglected Aspect

Parkinson's disease (PD) is now increasingly recognized as a disorder with myriads of motor and non-motor symptoms affecting the quality of life of the patients and their caregivers.

Although the therapeutic advances improve the condition to a large extent, it does not resolve all symptoms as there are various neurotransmitter abnormalities—noradrenaline, acetylcholine, and serotonin apart from the classical dopaminergic dysfunction.^[1]

Deep brain stimulation (DBS) of bilateral subthalamic nuclei (STNs) or the globus pallidi has now become an established treatment modality for patients with advanced PD and has been shown to provide significant improvement in motor and non-motor areas and quality of life of the patients, lasting at least 10 years after the surgery.^[2,3]

PD patients progressively depend more on their carers as the disease advances. Gait impairment, cognitive and behavioral dysfunction, and autonomic disturbances especially cause impairment of independence and constant requirement of a caregiver.

Caregiver burden (CB) is the stress accrued through caring for a sick family member or a loved one, which may have negative effects on the physical and mental health of the caregiver. In carers of PD patients, CB worsens with increasing disease duration and severity.^[4] The non-motor aspects, especially neuropsychiatric manifestations such as apathy, psychosis, hallucinations, and confusion as well as falls, seem to contribute maximally to stress and impairment of the quality of life of carers.^[5] Autonomic and sleep problems leading to higher time spent in nocturnal care also increase CB markedly. CB is less severely affected by the motor aspects.^[6]

Continuous dopaminergic stimulation is the treatment offered to advanced PD patients, and currently, levodopa carbidopa intestinal gel, continuous subcutaneous apomorphine infusion, and DBS are approved therapies. The improvement in off-time and quality of life seems to be more robust with levodopa-carbidopa intestinal gel and DBS.^[7]

The impact of CB does not have a linear relationship with the improvement in patients' symptoms and patients' functional capacity. Studies on levodopa-carbidopa intestinal gel and apomorphine infusion have shown an improvement in CB, more with the former.^[8] The effects of DBS are less certain. A recent systematic review of six studies did not show improvement in CB after DBS.^[9] Younger age and younger age at the onset of disease of the patients, shorter disease duration, lower medication requirements, and lower scores on psychiatric rating scales resulted in improvement in CB.

In the study by, Gencer GY, *et al.*^[10] have performed a cross-sectional analysis of the impact of bilateral STN DBS on CB. The carers were assessed 6–67 months after the surgery. Forty one percent of the carers reported a worsening of the CB, while 50% reported an improvement and the remaining had no change in CB.

The improvement in CB was attributed to the improvement in motor symptoms, while the worsening was thought to be predominantly due to impulse control behaviors and neuropsychiatric problems. This study is limited by the fact that it is a cross-sectional study with a small group, does not have a comparative group, does not compare the CB before and after the surgery, and does not address the impact of duration after surgery on CB. However, it still clearly brings out the major impact of behavioral issues persisting or appearing after DBS on CB.

As has been described by the authors, the impact of STN DBS on the non-motor aspects of PD is complex. A clear knowledge of the motor and non-motor changes in PD patient expected in the postoperative period, the requirement of time for hospital visits, the emotional turmoil, and the constant supervision required due to impulsivity post-surgery can help the caregiver have realistic expectations regarding the outcome. This can lead to better preparedness and improvement in CB.^[11] The duration after DBS has an effect on CB. The impulsivity and requirement for hospital visits come down with time despite the disease progression and can improve the CB. The science of DBS is expanding with the hope of better stimulation results, possibly adaptive DBS, and additional targets to treat non-motor symptoms such as cognitive impairment in the future, which may result in better patient and carer outcomes. In the meantime, choosing the right patient (younger age, shorter disease duration, and lower psychiatric burden), having a supportive environment for the carers, better understanding of the disease, and the outcome expected after DBS among the carers can all lead to an improvement in CB after DBS surgery for PD patients.

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