ORIGINAL ARTICLE

Deep brain stimulation for patients with Parkinson’s disease: Effect on caregiver burden

J.A. Crespo-Burillo a,*, D. Rivero-Celada b, A. Saenz-de Cabezón c, J. Casado-Pellejero b, J. Alberdi-Viñas b, R. Alarcia-Alejos a

a Servicio de Neurología, Hospital Universitario Miguel Servet, Zaragoza, Spain
b Servicio de Neurocirugía, Hospital Universitario Miguel Servet, Zaragoza, Spain
c Servicio de Neurofisiología, Hospital Universitario Miguel Servet, Zaragoza, Spain

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KEYWORDS
Anxiety; Apathy; Burden; Caregiver; Parkinson’s disease; Deep brain stimulation

Abstract
Introduction: Our aim is to assess the burden on caregivers of patients with Parkinson’s disease (PD) treated with deep brain stimulation (DBS) compared to those caring for patients at advanced stages and undergoing other treatments. We have also assessed the variables associated with presence of caregiver overload.

Material and methods: We included consecutive patients with PD treated with DBS. Our control group included patients in advanced stages of PD undergoing other treatments. Patients were assessed with the following scales: UPDRS-II, UPDRS-III, UPDRS-IV, Hoehn and Yahr, Schwab & England, Barthel, PDQ-39, MoCA, Apathy Evaluation Scale, HADS, and the abbreviated QUIP. Caregiver burden was evaluated with the Zarit caregiver burden interview and their moods were assessed with the HADS scale.

Results: We included 11 patients treated with DBS and 11 with other treatments. For patients treated with DBS, we observed a better quality of life according to the PDQ-39 questionnaire (P = .028), and a lower score on the HADS anxiety subscale (P = .010). Caregiver overload was observed in 54.5% of the caregivers of patients in both groups (P = 1.000); Zarit scores were similar (P = .835). Caregiver overload was associated with higher scores on the caregiver’s Apathy Evaluation Scale (P = .048) and on the HADS anxiety subscale (P = .006).

Conclusion: According to our results, treatment with DBS is not associated with lower caregiver burden. Apathy in patients and anxiety in caregivers are factors associated with the appearance of overload.

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Results from this study were presented at the 67th Annual Meeting of the Spanish Society of Neurology.

* Corresponding author.
E-mail address: josanjoseli@hotmail.com (J.A. Crespo-Burillo).

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Influencia de la estimulación cerebral profunda en la carga de cuidadores de pacientes con enfermedad de Parkinson

Resumen

Introducción: Nuestro objetivo es determinar el grado de carga de cuidadores de pacientes con enfermedad de Parkinson (EP) en tratamiento con estimulación cerebral profunda (ECP) con respecto a aquellos en estadíos avanzados con otros tratamientos y las variables asociadas a la presencia de sobrecarga.

Material y métodos: Se incluyeron de forma consecutiva a pacientes con EP en tratamiento con ECP, utilizando como grupo control a otros con EP en estadío avanzado sin ECP. Los pacientes fueron sometidos a una valoración mediante las escalas UPDRS-II, UPDRS-III, UPDRS-IV, Hoehn y Yahr, Schwab & England, Barthel, PDQ-39, MoCA, Apathy Scale, HADS y la QUIP abreviada. A los cuidadores se les estudió mediante el inventario de sobrecarga de Zarit y de valoración afectiva HADS.

Resultados: Se incluyeron 11 pacientes en tratamiento con ECP y 11 con otros tratamientos. En aquellos con ECP se observó una mejor calidad de vida según la escala PDQ-39 (p = 0,028), y una menor puntuación en la subescala HADS para la ansiedad (p = 0,010). Se observó sobrecarga en un 54,5% de los cuidadores de pacientes de ambos grupos (p = 1,000), con una puntuación similar en la escala Zarit (p = 0,835). La presencia de sobrecarga se asoció una mayor puntuación en la escala de apatía (p = 0,048) y en la subescala HADS de ansiedad en el cuidador (p = 0,006).

Conclusión: Según los resultados de nuestro estudio el tratamiento con ECP no se relaciona con una menor carga del cuidador, siendo la apatía del paciente y la ansiedad del cuidador factores asociados a su desarrollo.

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Introduction

Parkinson’s disease (PD) is a neurodegenerative disease causing a series of motor and non-motor symptoms which negatively affect patients’ quality of life. As the disease progresses, caregivers become essential to maintaining patients’ quality of life: their presence has been observed to decrease the morbidity and mortality rates of PD patients. On many occasions, the caregiver is a close relative, and will experience physical and emotional stress, changes to their everyday socio-economic activities, and, occasionally, overload.

In advanced stages of PD, different treatments have been proven to improve patients’ quality of life; one of these is deep brain stimulation (DBS). However, few studies discuss the effect of this treatment on the overload of PD patients’ caregivers. Our aim is to compare the degree of caregiver burden in cases of PD patients treated with DBS and patients with advanced PD receiving other treatments, and to identify the variables significantly impacting caregiver burden in these cases.

Material and methods

This is a cross-sectional observational study. We included consecutive patients treated at the movement disorders unit at Hospital Universitario Miguel Servet, Zaragoza, between September 2014 and July 2015. The study was approved by the Clinical Research Ethics Committee of Aragón.

We included patients with advanced PD who had been receiving treatment with DBS, continuous apomorphine infusion, or continuous intraduodenal levodopa infusion for more than 3 months. We also included patients with motor fluctuations who had previously received continuous apomorphine infusion or continuous intraduodenal levodopa infusion, which since had been suspended. We also included those patients for whom, at the beginning of the study, DBS, apomorphine infusion, or intraduodenal levodopa had been prescribed but had not yet started. All patients must have a main caregiver, defined as the person who lives with the patient and is directly involved in their care or directly affected by the patient’s health problem. We excluded patients whose main caregiver was a professional or belonged to a social support organisation, patients with moderate or severe cognitive impairment who were unable to understand or autonomously complete the questionnaires, and patients (or their caregivers, when applicable) who did not sign the informed consent form.

We gathered the following demographic data from patients: age, sex, and disease duration. We assessed disease severity with the Unified Parkinson’s Disease Rating Scale (UPDRS) subscales II, III, and IV and the Hoehn and Yahr, Schwab and England, and Barthel scales. Quality of life was measured with the 39-item Parkinson’s Disease Questionnaire (PDQ-39). Presence of sleep disorders was assessed using the Scales for Outcomes in PD (SCOPA) Sleep Scale, the degree of apathy with the Apathy Scale, the presence of mood disorders with the Hospital Anxiety and Depression Scale (HADS), cognitive disorders with the Montreal Cognitive Assessment (MoCA), and the presence of
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