

The impact of Deep Brain Stimulation on caregiver of people with Parkinson's disease: a systematic review of qualitative studies

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Introduction: Subthalamic nucleus deep brain stimulation (STN-DBS) represents an effective treatment in Parkinson's disease patients (PDPs). However, the effects of STN-DBS on caregiver burden (CB) of PDPs caregivers are still debated.

Objective: To explore the experiences and unmet needs of PDPs caregivers after STN-DBS by performing a systematic review and meta-synthesis of collecting and aggregating qualitative studies.

Methods: We conducted a systematic review of qualitative studies whose findings were synthesized after the critical appraisal. The search comprised five electronic databases: MedLine, Embase, Cinahl, PsycINFO and Scopus. Inclusion criteria for the meta-synthesis were (a) studies on the experience of CGs of PDPs post-STN-DBS, (b) English peer-reviewed articles, (c) qualitative or mixed methods studies reporting participants' quotations. Descriptive themes and conceptual elements related to PDPs CGs experiences and unmet needs were identified by performing the meta-synthesis.

Results: After duplicates' removal, 720 titles were screened, and only eight articles met the inclusion criteria. Three main categories (and related subcategories) were identified through the meta-synthesis: i) pre-STN-DBS: the starting situation characterized by the impact of PD on everyday life, the limitations to CGs' socialization and autonomy, and the CGs' effort in stepping aside for love and care activities; ii) post STN-DBS: signifying treatment-related changes with the feeling of being unprepared for changes (involving neurologists and professionals' communication), the fear and concern due to partners' behavioural changes, and the struggling to find an etiological explanation for those changes; iii) post STN-DBS: reconfiguring as caregiver and partner.

Conclusions: This meta-synthesis clarifies the meanings given by, and unmet needs of, caregivers of PDPs that underwent STN-DBS dismissing the idea of the unchanging symbiosis between caregivers and PDPs. STN-DBS treatment challenges the caregivers-patients relationship, according to the caregivers. Caregivers adequately supported from a psycho-social perspective will be able to accommodate a new role that is constantly to re-define.