Burden of normality and deep brain stimulation for Parkinson’s disease: A model of psychosocial adjustment

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Statement of the Problem: Deep Brain Stimulation (DBS) has become a leading treatment for alleviating the motor symptoms of Parkinson’s disease (PD). Patients may nevertheless experience psychosocial maladjustment after surgery. Initially conceptualized in epilepsy surgery, the burden of normality (BoN) has been viewed as an applicable model for addressing this issue in DBS for PD; however, there is a lack of empirical data supporting this assumption.

Methodology & Theoretical Orientation: We reviewed the literature to identify elements of psychosocial maladjustment in DBS for PD described in the three levels of the BoN: (1) precursory conditions: Chronic illness, sense of disablement and chance for dramatic cure, (2) clinical manifestations of psychosocial maladjustment and (3) two mediating variables: Pre-treatment expectations and discarding roles associated with pre-DBS PD. Next, we administered a DBS-adapted version of the semi-structured Austin CEP interview-designed to assess the BoN in epilepsy to 19 patients aged 58.8±10.1 years treated with DBS for PD.

Findings: The applicability of the BoN found strong support in the literature for each of the three levels, although no research addressed sick roles. Similarly, patients from the pilot study fulfilled the precursory conditions with a disease duration of 11.3±3.5 years, a low pre-DBS quality of life (SF-36 means: PCS=38.1±7.2, MCS=39.8±7.4) and a significant improvement of motor symptoms sustained in the long term (24.5±7.7 months, UPDRS-III: 28.5%, r=0.667, p=0.003). Qualitative data revealed that psychosocial maladjustment was characterized by psychological, behavioral, affective and sociological symptoms, which appeared to be fostered by unrealistic/ambivalent expectations and difficulties to forgo sick roles.

Conclusion & Significance: The BoN is useful to comprehend the post-DBS psychosocial maladjustment experienced by patients with PD and could constitute a theoretical basis for clinical rehabilitation.

Biography
Marc Baertschi has been working under the supervision of Alessandra Canuto on the psychological predictors of quality of life in patients treated with deep brain stimulation for a variety of movement disorders including Parkinson’s disease.

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