

DBS and the patient's lived experience: What can we say about the comparison between neurology and psychiatry?



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Neurosurgery in Parkinson disease

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A distressed mind in a repaired body?

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**Neurosurgery in Parkinson's disease: the doctor is happy,
the patient less so?**

**Y. Agid, M. Schüpbach, M. Gargiulo, L. Mallet, J. L. Houeto, C. Behar,
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Some PD patients:

- were not satisfied or did not experienced any social readjustment
 - complained that the stimulation did not work, that they did not feel the benefit of it
 - will ask that the parameters be adjusted, that stimulation be increased, or think that it has stopped.
- ⇒ They want to improve a state that is not only related to neurological motor criteria but to a more general personal context

A “body-mind rupture”: the psychopedagogical model

- At first, PD patients with social-adjustment problems were integrated into two of the team’s articles on the behavioral and cognitive problems induced by DBS or pharmacological treatment
 - These problems are not the result of DBS adverse effects (behavioral or cognitive disorders)
 - Psychopedagogical explanation: It is therefore *because* DBS improves the patient’s symptomatic state, radically and suddenly, that the patient is having trouble.
 - Patients are not always well prepared and need to be informed
 - DBS is seen to cause a rupture in the patient’s life (biographical disruption) (Gisquet 2008)
- ⇒ “They sometimes have problems when they return to social life. Their family and friends are not ready for the new person, not accustomed to him or her. It is like getting out of jail. There is an appetite for life.” (a neurologist)

ORIGINAL CONTRIBUTION

Subthalamic Stimulation in Parkinson Disease

Behavior and Social Adaptation

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PAPER

Behavioural disorders, Parkinson’s disease and subthalamic stimulation

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Opening the ethical debates in DBS for PD



- These unhappy patients were a minority, never quantified on account of the absence of strict criteria to characterize them (rather, they were placed under a default categorization for lack of any other explanation) and especially of their variability
- This is expressed – contrary to the rest of the literature – through the insertion of several clinical vignettes. They need to report this ill-being, which evaluation scales sometimes identified but were not able to express in its complexity
- 20 years after the first surgery: These publications have initiated the philosophical and ethical debate about DBS for Parkinson's disease (identity, continuity of the self, autonomy, risk/benefits, etc.)

frontiers in
INTEGRATIVE NEUROSCIENCE

Ethical issues in deep brain stimulation

Preparing the ethical future of deep brain stimulation

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Did My Brain Implant Make Me Do It? Questions Raised by DBS Regarding Psychological Continuity, Responsibility for Action and Mental Competence

Laura Klaming · Pim Haselager

The “Vulnerability” of Psychiatric Research Participants: Why This Research Ethics Concept Needs to Be Revisited

Dearbhail Bracken-Roche, BSc^{1,2}, Emily Bell, PhD¹, and Eric Racine,

Stimulating brains, altering r

W Glannon

“DBS means everything – for some time”. Patients' perspectives on daily life with deep brain stimulation for Parkinson's Disease

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« Personality disorders are killing our resources » (a neurologist)



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Scientific and Ethical Issues Related to Deep Brain Stimulation for Disorders of Mood, Behavior and Thought

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DBS impractical for some patient populations. DBS also carries risks and burdens, such as stimulation interruption due to battery depletion, not present in lesioning. As such, researchers should investigate treatments that might produce equivalent results without DBS's high costs and ongoing need for follow-up care. That said, and in contrast to lesioning approaches, DBS does have the clinical and ethical advantage of being potentially reversible (barring serious adverse events related to surgery). This is a relevant consideration for comparative studies of DBS and lesioning approaches both for targets that have and have not been prior targets of lesioning, and must be weighed along with the other factors mentioned above when considering such studies.

“I’m okay, but not doing very well.”

OCD and social adaptation



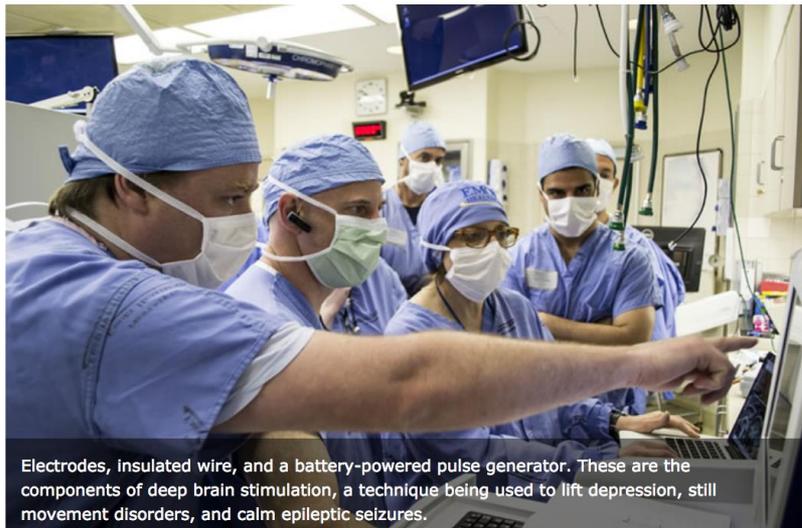
- OCD patient daily life had been demolished by the disease, and now, with their OCD alleviated, they must build a new life on the ruins of the old one

“I suffer from loneliness, I’m all alone, and then my father died two years ago, and then my mother has Alzheimer’s disease. She’s in a retirement home but she doesn’t get very good care, that’s what I’m worried about, so I have to change her [retirement home]. And then I’m having problems with the takeover man [taking over the family company]. All that... I shouldn’t have had to have trouble with the stimulation settings, I shouldn’t have had to have worries, and then I’m alone, I’m suffering from loneliness, but well, I sometimes think about getting back together with someone, with a woman (...). But the OCD is 70% better.”



Targeting depression with deep brain stimulation

By Sylvia Wrobel | Emory Medicine | April 27, 2015



Electrodes, insulated wire, and a battery-powered pulse generator. These are the components of deep brain stimulation, a technique being used to lift depression, still movement disorders, and calm epileptic seizures.

Slide show of the deep brain stimulation (DBS) team at work. DBS involves surgery on a patient's skull, with precise placement of electrodes that will be connected by a thin wire to a battery-powered pulse generator implanted under the collarbone.

Photos by Michael Konomos, Emory University.



After three decades of severe depression and trying nearly every treatment, deep brain stimulation helped Marjorie Stowe (above with daughter, Maddie) reclaim her life and regain the ability to feel joy.

The “psychotherapeutic” model



- Social maladaptation and worsening of functioning are ethical criteria to experiment DBS for OCD (in DBS for PD: social maladaptation is a consequence of DBS effect and lack of information)
- A “psychotherapeutic” follow-up care: once the symptoms have been reduced under the effect of DBS, it aims to support and to accompany the patient in his/her social reintegration and adjustment process (listening, supporting, counseling + psychopharmacological prescription)
- « It gives access to another dimension of the disease » (a psychiatrist)
- DBS as a « potentializer of social rehabilitation » (vs psychopharmacology as a « potentializer of psychotherapy » in the 60’: Ehrenberg, 1998)

The difference between neurology and psychiatry



- Lesion vs function, capacities vs functioning
- Mayberg about DBS for depression: « You are changing the whole person »
- Schurrman: « Depression is more a state of the brain or person, or both, rather than tic that comes and go »