



# Neuromodulation Technologies and the Regulation of Forms of Life. Exploring, Treating, Enhancing

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# **Neuromodulation Technologies and the Regulation of Forms of Life: Exploring, Treating, Enhancing**

## **Abstract**

Today, deep brain stimulation (DBS) is one of the most innovative treatments for a range of neurological and psychiatric conditions. As the practice spreads worldwide, this invasive neurosurgical technology has become the subject of major social, scientific, and ethical concerns about its regulation. In this article, I describe its implementation in a French neuroscience ward and the different forms of practice that structure and promote the development and circulation of this neuromodulation technology. I explore how alternative experimental uses of DBS and deviations from its original therapeutic objectives both interfere with and promote its dissemination. At first, it appeared that neuroscientists could use DBS as a powerful tool to create reproducible experimental human models of emotional or behavioral symptoms so as to explore the functions of the human brain in vivo. In parallel, implanted patients influenced the care program by viewing DBS as a potential technology of self-enhancement for a wide range of personal situations. These alternative uses of DBS have challenged its modes of regulation and standardization and have raised new medical, scientific, and moral controversies. These concern not only ethical and methodological norms of medical and scientific practices, but also the anthropological tensions raised by the forms of life that are emerging from neuroscience and experimental practices.

**Keywords:** *forms of life; medical experimentation; neuroenhancement; neuromodulation; neuroscience*

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# **NEUROMODULATION TECHNOLOGIES AND THE REGULATION OF FORMS OF LIFE:EXPLORING, TREATING, ENHANCING**

**Baptiste Moutaud**

In 1986, a lucky clinical observation during a neurosurgical intervention on a patient suffering from Parkinson's disease led the French neurosurgeon Alim Louis Benabid to conceive of a new treatment for the neurodegenerative disorder. While he was electrically stimulating a cerebral area of the patient's brain with high frequency currents, he observed the suppression of the patient's motor symptoms. A few months later, he introduced a new therapeutic intervention, deep brain stimulation (DBS) (Benabid et al. 1987). The basis of this neurosurgical technology is the modulation of cerebral activity by means of electrodes implanted in patients' brains, mainly in the basal ganglia, a group of nuclei situated deep in the brain. These electrodes are connected to a battery placed in patients' chests, enabling long-term stimulation. The clinician can then alter the stimulation parameters (frequency, voltage and impulse duration) by telemetry, according to symptoms and side effects, using an external programmer.

After a decade of experiments, DBS was recognized as a reference therapy for certain forms of Parkinson's disease and replaced lesional procedures.<sup>1</sup> DBS is now used primarily for patients for whom chemical treatment (levodopa) has ceased to be effective on symptoms, and for whom it induces pervasive and disabling motor side effects (dyskinesia, repetitive involuntary body movements). For this population, several clinical trials have established that DBS efficiently improves motor symptoms (shaking and rigidity) and allows reducing medication even if, as we will see, several complications at times appear under stimulation (Volkman 2004).

In the early 2000s, the technology started to spread widely.<sup>2</sup> Furthermore, its application was experimentally extended to a wide range of neurological and psychiatric disorders, in

particular dystonia (in 1999 in Canada and France), Tourette's syndrome (in 1999 in the Netherlands), obsessive-compulsive disorder (in 1999 in Belgium) and depression (in 2005 in Canada). There are now many clinical trials underway worldwide to assess the safety and efficacy of DBS in forms of these conditions that are resistant to conventional treatments (for example, pharmacology or cognitive behavioral therapies in the case of psychiatric disorders). According to Medtronic, the largest DBS device manufacturer, over 100,000 patients have undergone DBS worldwide.<sup>3</sup> Today, new candidate conditions are discussed or experimented on, such as eating disorders, minimally conscious states, addictions (alcohol, heroin, and cocaine), multiple sclerosis, bipolar disorder, schizophrenia, and Alzheimer's disease (see Chen et al. 2013).

Through this expansion of applications, DBS became a central issue not only in functional neurosurgery, neurology, and psychiatry, but also in contemporary neuroscience, whether in terms of fundamental research or for the purposes of care and treatment. DBS has become a priority in neuroscience research planning in many countries, largely due to neurologists' and psychiatrists' hopes that the technology might provide solid evidence of the increasing potential of neuroscience to treat neurodegenerative diseases or psychiatric disorders in the near future.<sup>4</sup> Already, the success of this discovery and the expansion of uses of the intervention resulted in Benabid receiving the Lasker Award in 2014.

Among the scientific and medical challenges that have accompanied the development of neuroscience over the last 30 years, the ability to act directly on the brain to modulate its functions so as to treat illnesses or even improve individual performance stands out. Aside from neuroscientists' philosophical claims that their discipline will reveal the fundamental nature of human life, neuroscience can be defined as an aggregate of medical and scientific disciplines (such as neurobiology, cognitive sciences, neuroanatomy, psychiatry, neurology or pharmacology) sharing a common project: the study of brain anatomy and functioning in

order to (1) identify and explore the neural basis of cognitive functions, thought, emotions and behaviors, and (2) discover the causes of neurological and psychiatric disorders and to elaborate therapeutics. However, considering the means available, the discourses generated, and their symbolic positioning in the public space, therapeutic innovations in neuroscience have been relatively few in number since the 1980s. In this respect, many expectations about the potential of neuroscience to develop innovative treatments have been oriented toward DBS (and more broadly neuromodulation technologies).<sup>5</sup> This technology and its applications have therefore received a great deal of attention from the general public, while at the same time raising many ethical, medical, and social issues (Gilbert and Ovadia 2011; Racine et al. 2007).

Two lines of discourse have so far monopolized the ethical, medical and social discussions of DBS. Considered together, they highlight the controversies of the field. The first discourse appears cautious and preventive and belongs to practitioners themselves (neurosurgeons, psychiatrists, and neurologists). While exploring the historical development of the technology, they aim to regulate and protect the technology from excesses of hope and applications, especially since DBS has renewed the interest of psychiatrists and neurosurgeons for the surgical treatment of mental disorders (for instance, see Benabid's article provocatively entitled "Beware! Psychosurgery is back!", 2006; see also Moutaud 2014).<sup>6</sup> The second type of discourse is bioethical, and aims to arbitrate the moral issues raised by DBS. To bioethicists, DBS empirically underlines what it is or is not possible—or what might be desirable, ethical, or moral—to do to a human being in order to provide care or to enhance cognitive and/or emotional capacities (e.g. Glannon 2014; Koivuniemi and Otto 2014). Both these approaches suggest that DBS interventions and experimentations are a starting point for questioning neuroscience knowledge and practice, and the acceptable forms of existence for mankind they are ultimately producing. But at the same time they contribute to generating

standards of practice (Bateman 1998; Tournay 2006). These discourses are therefore statements that should be examined in the light of actual practices and in relation to medical or social interests and organizational or economic factors.

Focusing on the individual identities and the material bodies produced through DBS clinical and experimental practice, I will describe how alternative experimental uses of this technology and deviations from its original therapeutic objectives both interfere with and promote its dissemination. DBS is a compelling example of neuroscience leaving the laboratory to inhabit bodies and modify individual experience. As an invasive biomedical technology, DBS does not merely alter representations of diseases; it reconsiders and reconfigures the links between body, individual and identity, and their co-productions (Lock, Young and Cambrosio 2000; Hacking 2006; Rabinow 1996). As a result, I am interested in tracing the outlines of the various forms of life, or human ontologies (i.e. what kinds of human are present in concrete situations, see Piette 2012) and identities that are emerging from the use of this medical technology. I seek to apprehend empirically how the material reality of bodies and identities are produced and enacted through this biomedical innovation according to time and place, and how they co-exist (Mol 2002).

Several authors have described how neuroscience—its practices, knowledge, technologies, therapeutics, discourses—contribute to shape a new form of existence for the individual, a new manner of seeing him/herself and of defining his/her personal identity and relational life in accordance with his/her brain and its functioning (e.g. Dumit 2003; Ehrenberg 2004; Rose 2003; Vidal 2009). If we follow Stanley Cavell (1989), “forms of life” can be defined as the tension between a human beings’ biological basis (life and its emergent forms) and the rules that govern social relations (the cultural forms of social life). Neuroscience seems to offer new collective or individual means to negotiate the tension and the variety of modes of existence that could emerge between these two continua. My point

is therefore to clarify how human beings' new forms of existence produced through the DBS applications are discussed, regulated, or become object of controversies, and how they could hinder or accelerate the circulation and use of DBS. In this article, I therefore focus not only on the potentialities opened for implanted patients to reconfigure their world, but also examine the life forms this hybrid between a human being and technology allows researchers and clinicians to elaborate.

In order to do this, I will describe how neuroscientists began to use DBS as a powerful tool to create an 'experimental body,' a reproducible experimental human model of emotional or behavioral symptoms, so as to explore the functions of the human brain in vivo. In parallel, implanted patients influenced the care program by viewing DBS as a potential technology of self-enhancement for a wide range of attributes and personal situations. I will then explore how these alternative uses of DBS have challenged its modes of regulation and standardization and have raised new medical, scientific, and moral controversies. These concern not only ethical and methodological norms of medical and scientific practices, but also the anthropological tensions of the potential new forms of life produced by the use of this neuromodulation technology. These issues will be explored by focusing on the local deployment of DBS in a French university hospital department dedicated to clinical research in the area of neuroscience.

#### "WHAT DID YOU DO?" AN ETHNOGRAPHIC VIGNETTE

There was this patient who would call Katya [the neurosurgeon] in the night to say he was in love with her. He was readmitted to the neurology department, and we altered the stimulation. And lo and behold, he didn't want to marry her anymore!

Vincent, neurologist



Combining fundamental research in neuroscience and medical experimentation in psychiatry and neurology, the French department team, comprising clinicians and researchers (psychiatrists, neurologists, neurosurgeons, psychologists, neuropsychologists, anatomist, brain imagers, etc.) has historically been one of the most innovative and pioneering centers in the world for DBS and its applications.<sup>7</sup> Members of the team started implanting Parkinson patients in 1996, and developed clinical trials for the treatment of various neurological or psychiatric conditions such as dystonia, Tourette's syndrome, OCD, addiction or depression. Between September 2004 and December 2008, I conducted ethnographic research in this ward. I was interested in describing how this research team had operationalized the translation of DBS from neurology to psychiatry and how they legitimated it, redefining the frontiers of practice but also reconfiguring the disease definition and patients' experience (Moutaud 2009). This research took place at a time when DBS research and practice was undergoing profound reconfigurations: questions were being raised concerning its extension from neurological to psychiatric indications as well as the very nature of DBS effects and follow-up required by patients as a result. Importantly, this ward initiated or actively participated in these debates, debates that still deeply impact on the diffusion and regulation of the technology.

In a team meeting in 2006, Vincent, one of the team's neurologists, described a consultation he had had with a patient suffering from Parkinson's disease who had been implanted. The stimulation had been adjusted and there had been good hopes that his motor symptoms would improve, as was indeed the case. However the patient had returned a few days later with his wife, who told the neurologist that once they got back home, the patient's behavior had changed. He had become restless and hyperactive, talking incessantly, interrupting her and even behaving aggressively. Vincent explained that he consequently

changed the stimulation parameters, warning the patient that he might feel the motor symptoms were a little less well controlled. He then referred the patient to Hadrien, the team psychiatrist, for assessment. When Hadrien saw the patient, he noticed nothing in particular, and wondered why he had been referred. He reported that the patient's wife then told him that her husband had stopped his incessant talking upon leaving Vincent's consulting room. After several clinical evaluations, both clinicians agreed that the initial stimulation settings led to a situation in which DBS had caused reversible symptoms of hypomania.<sup>8</sup> Hadrien concluded: "and that's where the story [of their research] starts".

From the 2000s, neurological and psychiatric literature reported numerous cases of behavioral or emotional side effects generated by DBS among Parkinson patients. The reports concerned a wide range of effects, such as depression, pathological gambling, hypersexuality, episodes of rage, neurological laughter, or even a sudden passion for Johnny Cash (see Castrioto et al. 2014, for example). These effects appeared (sometimes after only a few seconds) during or after surgery, while clinicians were adjusting the stimulation parameters. Symptoms of hypomania and mania were the most frequently reported. They appear close to psychopathology and are spectacular in that they involve complex, subtle behaviors. This was true of the patient mentioned above, a case that was soon followed by a second. Subsequently, Hadrien used these two cases in conferences to introduce the research in his team. In the illustrative videos he showed about the cases, the first of these two implanted Parkinson patients, aged around fifty, is seen being interviewed by a psychiatrist. He describes a party he has just organized in his home with neighbors. The evening seems to have been good fun, with 'ball games' and 'beach games' in his garden and swimming pool. There are a few other anecdotes that nevertheless suggest he had been behaving strangely in the days surrounding the party and video production. He is tense and restless. The video then shows his wife, who among other things explained that "he is very agitated, he talks all the

time and is very bad-tempered”. He even became aggressive towards her and slapped her. The following scene shows the patient, this time surprisingly calm. He says he feels ‘slow’, but that the medical team “did not want to leave [him] euphoric”.

In the second case, the scene takes place in a consultation cubicle where Hadrien and Elizabeth, one of the team's neurologists, see a patient. The video shows a woman who is agitated, talking loudly, explaining that she is ‘over-excited’ and ‘yells’ rather than talks. Hadrien asks her if this is “very different from what you are usually like? Were you never like this before?” She answers: “I’m over-excited—why am I like that? I’ve never been this way in all my life. I’m fed up with being like that. Something inside me has changed, but I don’t know what.” Elizabeth is then seen changing the parameters of the stimulation. In a new video shot a few minutes later, the woman says: “I feel less agitated. I feel better, I’m back to normal. Well, if you can call that normal...” In a further video shot the following morning we can see the patient, who appears more calm, explaining that she feels “a lot less agitated, less strength in my muscles. I am calmer. I feel I’m in a normal state. Yesterday I wasn’t my normal self. I’m better. What did you do?” Hadrien then informs the audience that in each case, the stimulation zone has merely been shifted a few millimeters in the brain structure where the electrodes were implanted.

The narrative takes on a new dimension when we learn that the team obtained consent from both patients to reproduce the effect over 24 hours for research purposes. In light of the many case reports published by other research groups, the team aimed to distinguish itself by (1) reporting the precise localization of the electrodes in the brain and (2) correlating the results with a clinical investigation of patients in both stimulation conditions (i.e. with and without symptoms of hypomania). The case study was informed by functional brain imaging findings and motor, cognitive and behavioral assessments carried out at each consultation. The publication of the results in 2007 was an important landmark for the team and the

article became a reference in this area. This research led the team to develop a general theory of brain function, at once explaining the effects of DBS on behavioral symptoms and justifying its extension to psychiatric disorders. The focus of the present paper is the entities, forms of life and forms of practice and their co-production that emerge from this research.

## PRODUCING EXPERIMENTAL HUMAN BODIES, EXPLORING THE HUMAN BRAIN IN VIVO

The ethnographic vignette presented above illustrates the roots of the shared interest in DBS on the part of neurologists and psychiatrists, whether clinicians or researchers, and even more so among neurosurgeons, neurophysiologists, anatomists, neuroimaging practitioners, psychologists, neuropsychologists and so forth. Indeed, in addition to being seen as a potential therapeutic technology for a whole range of conditions, DBS makes it possible to develop experimental clinical models of behavioral disorders in humans, and enables functional exploration of their neural foundations. In this sense, and independently from the issue of its efficacy, the technology is a powerful tool for functional in vivo exploration of the human brain. It feeds research on the links between motion and emotions and between behaviors and mental states, which are central issues in neuroscience and in the long-debated relationship between neurology and psychiatry (Moutaud 2015).

This use of DBS is part of the long-established neurophysiological culture in which electricity is enrolled to conduct functional brain exploration (see Borck 2009; Finger 1994; Leigh Star 1989). Several DBS researchers who have attempted to retrace the origins of the technology have indeed referred to this link (e.g. Butler, Rosenow and Okun 2008; Gildenberg 2005; Hariz, Blomstedt and Zrinzo 2010; Schwalb and Hamani 2008). However these are internalist and “recurrent histories” (*histoires récurrentes*, Canguilhem 1983: 183) concerned

with the technical development of DBS. They are characterized by their irreversibility, painting a linear trajectory of scientific discovery and medical progress disconnected from any social, institutional or organizational contexts or interests. They do not reflect the variety of care or research practices resulting from the application of DBS to neurological or psychiatric disorders. One of the figures regularly included in these narratives is the Canadian neurosurgeon Wilder Penfield (1891-1976). Inclusion of this father of modern neurosurgery is indeed difficult to avoid, but as his actual implication in the history of DBS is never really specified—perhaps owing to researchers’ beliefs that his role is obvious to readers—he simply serves as one of many of ‘heroic’ figures in the field.<sup>9</sup> However, I will describe how the reference to Penfield’s practices cast light on the paradigms underpinning the experimental use of DBS, its exponential development (in particular compared to less invasive or non-invasive procedures, such as vagus nerve stimulation or transcranial magnetic stimulation), and the shifts brought about in the way knowledge is produced in neuroscience.

Penfield developed a surgical methodology from a neurophysiological investigative technique using electric stimulation, which revolutionized the possibility for clinical observation and learning in operating theaters. Using this technique, any neurosurgical operation could provide scope for functional exploration of the human brain. Thus in the course of surgical interventions on patients under local anesthesia, he systematically practised a series of stimulations of the cortex. During operations, once the skull was open and the cortex accessible, Penfield subjected a given cerebral zone to electrical stimulations. An assistant remained beside the conscious patient so as to note the clinical signs triggered by these successive stimulations, and to question the patient on what s/he was experiencing. The stimulated zone was then correlated with the clinical observations. This functional mapping, known as the Montreal Procedure, was performed on hundreds of individuals, yielding new

maps of sensory-motor functions in the cortex, and numerous observations and discoveries on the functions of language, memory, behaviors, and emotions (see Eccles and Feindel 1978).

This procedure was a turning point in knowledge, and above all in the means for producing knowledge, of the brain for two reasons. Firstly Penfield shifted the location of the production of knowledge: experimental neurophysiological knowledge of the brain was no longer confined to the physiology laboratory and animal experiments. It was obtained in the operating theaterexperimenting directly on human subjects. Penfield's research methods radically changed the temporality of observations by developing experimental human models of clinical signs and neurological functions. Indeed, unlike a brain lesion, electric stimulation makes the experimental model reproducible in a number of different individuals as well as repeatable in the same individual. Overall, unlike clinical and anatomopathological approaches based on particular cases of neurological deficits and disorders, Penfield's approach afforded the possibility of observing the sign, recording the subject's reported experience, and obtaining the physiopathological cause in a specific time lapse, all in controlled and reproducible manner (Forest 2005:69). He set research issues alongside clinical data, combining functional neurology, neurophysiology, experimentations and therapy in a single, reproducible procedure. As a result, he is credited with laying the foundations for functional neurosurgery, and above all having systematized the methodological paradigms involved.

What is interesting here is that DBS has moved beyond this procedure in time and space. It enables experimental clinical models of behavioral disorders in humans to be developed and repeated on the same individual alongside the functional exploration of the neuronal foundations of behavioral disorders, not only in the operating room but also in the consultation room. This is described above in the cases of the two patients under stimulation who developed symptoms of hypomania. DBS is adaptable and reversible and its technical

characteristics allow it to move on from mere empirical, transitory observations on several different cases to an approach seeking to reproduce phenomena before assessing them. By radically altering the temporality of clinical observations in this way, DBS contributes—in patients in their therapeutic setting so long as the device remains implanted (i.e. for life)—to producing an ‘experimental body.’ For Ilana Löwy (2000) this ‘experimental body’ is an entity enabling the exploration of normal and abnormal functioning of the human body for the purpose of generating “scientifically credible knowledge” (Lock and Nguyen 2010:180). Here, the patient as an experimental body is a life form, an entity easier to control than the living body captured in the bustle of life. This life form is most often restricted, for ethical and methodological reasons, to laboratory animals, or to a strict setting of clinical trials. However, while Penfield opened the way to a new temporality in the operating room, DBS does away with the boundaries between treatment and research in the very act of caring for patients in the operating theatre as well as in the consultation room.

The experimental body is enacting the neuropsychiatric and neuroscience program in practice (Brosnan and Michael 2014). It is the subject of perusal by multiple gazes and affords a shared space and time for the convergence and translation of various interests (neurological, psychiatric, neuropsychological, neuroanatomical, and so on). It becomes a “trading zone” (Galison 1997:783–784), giving form to collaboration among viewpoints, questionings, and heterogeneous aims. It enables collective exploration of phenomena that it contributes to rendering visible. Therefore teams can establish neuropsychiatric devices based on DBS and on these experimental bodies. These devices are *neuropsychiatric* in the sense that in the brain they directly explore links between motion and emotions, behaviors, and mental states, and enable these different functional dimensions to be manipulated experimentally. Thus the therapeutic technology has the dual function of also being a powerful tool for research and investigation, of interest to both clinicians and researchers in the terms of future applications. It

offers a program for action, and “organizational efficiency” (Abbott 1988:193–194; see also Löwy 1997:53): the issue of treatment efficacy is temporarily subordinated to the ability of the technology to combine interests, and create modes of organization and collaboration around its applications.

Nevertheless, this use of DBS as a technology to explore brain functioning has not failed to raise questions among researchers in the area as to the very nature of the procedure and the status of patients used in this research. In the following section, I set out the main lines of these debates.

## REGULATING INTERESTS AND CONTAINING ENTHUSIASMS: CARING FOR BODIES AND PATIENTS

While the multiple uses of DBS has facilitated its rapid diffusion, its hybrid nature as a clinical/research technology has made attempts to identify the forms of practice it enables extremely complex. The challenge of this complexity is even more evident in discourses surrounding its scientific and ethical regulation. Therefore these ‘experimental bodies’ are at the core of numerous debates on different structural, ethical and epistemological levels, all intersecting.

The experimental models of behavioral disorders or hazardous side effects observed on patients stimulated via DBS raise questions for researchers about the value of what these cases appear to demonstrate, and of their appropriate place in practice. These experimental models or hazardous side effects are often mobilized as a major argument to initiate new therapeutic applications, or to justify experimental implantations in new cerebral target areas. Among the most recent instances, we can cite the case of addictive behaviors (e.g. pathological gambling or hypersexuality) triggered or improved in Parkinson patients, thus



orienting teams towards the treatment of addictions (see Hall and Carter 2011). Researchers have also observed effects on memory recovery in the case of a single patient that led to applications of DBS in Alzheimer's disease (Hamani et al. 2008), and more generally the side effects on the emotions, contributing to the extension of DBS to neuropsychiatric or psychiatric disorders (e.g. Mallet et al. 2002).

Debates within neuroscience literature have not only focused on the clinical dimensions of the phenomenon to which these experimental models or side effects are thought to relate. These debates have also included epistemological concerns about the demonstrated value of these cases, often singular and very little investigated clinically or in their biological basis, within an evidence-based regime of biomedical practice regulation. In this highly competitive area of practice, there have been calls in the scientific community to moderate enthusiasm, remarking that existing cases do not provide adequate justifications for claims of innovation (Schlaepfer and Fins 2010).

It is not however on this level that I focus here. For certain clinicians or researchers involved, particularly those in the center where my research was conducted, the problem raised by the rapid growth of experimental DBS practice does not reside solely in taking shortcuts or disputing the standard modes of scientific regulation of medical practice (the risk being to end up side-stepping ethical and deontological rules). The risk is rather that the technology could diffuse too rapidly in view of the clinical and technical competence and the structural means required for its deployment.<sup>10</sup> This would lead to these 'experimental bodies' being integrated into care plans and environments that are problematic, which would mean, as I describe below, that much wider medical and economic issues are at stake. Indeed, while every behavioral, emotional or cognitive side effect is potentially a source of knowledge and innovation for the teams involved, it requires clinical expertise and considerable organizational investment to provide care for the patients who undergo DBS interventions.

As in the exclamations of the second patient quoted above, individuals who have experienced hypomania side effects reported a puzzling and upsetting experience, for which they have understood neither the causes nor the mechanisms. For instance, Melville, a patient who was suffering from OCD and was implanted by the team within the context of a clinical trial, spoke to me of his experience of what the team described as an episode of hypomania:

I don't know if [Elizabeth] set it too high, but on one occasion I was very agitated when they put the current back on [the stimulation]. I wasn't supposed to know [the procedure was double-blind], but I felt it because when I got home all I could do was talk, I was running round in circles, I wasn't eating, I wasn't sleeping. After that I was admitted to emergency [psychiatric ward]. I was so agitated they thought I was mad. I couldn't stop walking around the bed. They put me in isolation, and it was there that I noticed there were fluctuations: sometimes I was alright, and then I started going mad again. At times I was very down, I thought they had shut me away to do experiments, I was starting to go mad. (Interview, March 05, 2009).

Melville's words highlight the fact that patients under stimulation have no control over these side effects, nor more widely over DBS. Unlike pharmacological treatments that a patient can adapt or discontinue, the only resort for these patients is to return to the hospital to request that clinicians alter the stimulation parameters (if, as Melville, they were not hospitalized in emergency). This feeling of "loss of control" (Gisquet 2008) can be amplified by the fact that the technology is still experimental and mostly empirical concerning the adjustment of stimulation parameters settings, as a result of both the uncertainties as to the mechanisms of action of DBS (debate is still open on the way in which DBS operates, see Kringelbach et al. 2010) and the causes of the side effects observed. The corollary of this absence of room for maneuver can be that the patient feels him/herself to be dependent on the technology and on the solutions offered by the healthcare team and its competency. The ideals

of autonomy that underpin care plans today are thus removed from this new ‘technical’ relationship. In addition, this loss of autonomy in the management of treatment leads patients to call on practitioners more frequently. In the center studied, this has led to a saturation of the care program, and has required the structure to be adapted to cope with the influx of demands (Moutaud 2011).

These questions became particularly crucial in the center where my observations were conducted when certain patients themselves expressed the desire to redirect or reorient the effects of DBS, making it a potential biotechnology of ‘self-enhancement’.

### DBS AS ABIOTECHNOLOGY OF THE SELF?

DBS has become the terrain of inquiry of ethics in neuroscience, in particular focusing on the subject of changes of individual autonomy and responsibility, or on the use of DBS as a technology for the enhancement of capacities (see, e.g. Glannon 2009; Hildt 2006; Klaming and Haselager 2013). In France for instance, in December 2013 the national ethics committee issued a statement on the ethical challenges of neuroenhancement where DBS, among others neuromodulation devices, was a choice because of the scope of possibilities it might offer individuals to improve their mental or cognitive capacities (Comité consultatif national d'éthique pour les sciences de la vie et de la santé 2013). However, as the French national ethics committee put it, there is in fact no actual practice of neuroenhancement by DBS, and certainly not on individual patient initiative—since as seen above, patients cannot adjust stimulation parameters on their own. But the committee defines enhancement narrowly as an objective improvement of psycho-cognitive capacities. By contrast, it has been suggested that the notion could cover an array of situations interrogating the relation between the normal and pathological and individuals’ subjective experience.

According to Bateman and Gayon (2012), questions concerning human enhancement relate to three conceptually distinct meanings and three levels of analysis (practical, general, individual): the enhancement of capacities, which relates to actual practices; the enhancement of human nature, which belongs to philosophical, moral and political discourse and debate, allied in particular to ‘transhumanism’; and the enhancement of the self, taking the form of subjective interpretation of practices by individuals, which is related to the anthropological question of self-fulfillment. I will explore this third level through the case of implanted Parkinson patients who viewed DBS as a technology of self-enhancement for a wide range of attributes and personal situations. I describe how DBS could produce a rupture in the way stimulated patients understand the relations between their biological existence and their social life and how these relations subsequently influenced the care program and the DBS regulation.

Parkinson patients implanted in the research center, according to clinicians, had improved motor symptoms and were not experiencing side effects, but were nevertheless “not satisfied” (a neurologist). I saw one of these patients (among others) during my fieldwork while he was at a consultation with the neurologist. On that day, he entered the room and explained to the neurologist that he “was blocked”: “It’s as if the stimulator had stopped,” he said. The neurologist was surprised. The stimulator was functioning properly at that moment and it could not have stopped and started up again on its own. He examined the patient and then increased the stimulation radically while saying: “3.6 volts, 185 Hertz, and 90 milliseconds.” He explained to the patient that it had nothing to do with a “blockage”: “It’s a weakness, a generalized fatigue.” He reminded the patient that at the beginning of stimulation, he was well, but afterwards, he was “never satisfied,” that he had said he “still had a problem of rigidity on the right side.” For the neurologist, the patient’s complaints were linked to unrelated issues and the origin of the problem was not linked to residual motor symptoms. However, the patient was not here for the first time. I had observed almost the same situation the week

before and months ago with the same patient, and the neurologist told me that he consulted on a very regular basis, ironically calling him his “favorite patient.”

As was the case for patients who were experiencing side effects, these patients were also challenging the care program and its rationalization. They were in varied social and medical situations and expressed different reasons for dissatisfaction. These ranged from what they (or the team or their relatives) perceived as social maladaptation (for instance they had divorced or left their jobs) to complaints that the stimulation was not functioning, that they could not feel its effects, or the appearance of new problems in their lives (such as problems with their partners, fatigue, general uneasiness, loss of energy, etc.). As patients are provided with psychopedagogical explanations for these situations (DBS is seen as causing a rupture in the patient's life and they—or their relatives—are not psychologically prepared), the central issue for the clinicians (and my analysis) lies in that some of these patients considered DBS to be the cause of and/or the solution for their problems. They came to consultation to ask the neurologists to adjust the parameters: to be increased, for instance; wondering if it had stopped; in some cases, the spouse made the request, asking the neurologist to turn it off. Some of them even asked for the external programmer in order to be able to control the stimulation by themselves.

As I have suggested elsewhere, these implanted patients ‘naturalize’ their problems, trying to use the technology and its effects as a new model of causality (Moutaud 2011). DBS can then become a tool for self-enhancement (which could not be simply limited to enhancement of capacities), a “biotechnology of the Self” to return to the notion set out by Lock and Nguyen (2010:284). In contrast with the experience of the ‘experimental body’, using DBS as a biotechnology of the self—via their care provider—might offer individuals the possibility of acting on their brain function in the hopes of recovering control over their destiny, of becoming agents of their own change, with the prospect of re-inventing

themselves. This enables them to objectify their experience as they aim to control their trajectory by determining the resulting lines of conduct. Their hope echoes that portrayed in Rose and Abi-Rached's analysis of neuroscience (2013) as initiating a brain economy where the organ becomes the preferential object and target for individual and collective interventions in order to define what we could or should become. This attempt to reorient the use of DBS produces a new form of life: it allows these individuals to reappraise the links between the fundamentally biological dimensions of their existence, their social identity, and their relationship to the world. But above all it enables them to act on these links. However, this form of life is then not so much the construction of a new biosocial identity (a kind of 'biosociality', where people identified themselves to a new common biological ground in order to develop new forms of collectives or socialities, Rabinow 1996) as it is an idiom mobilized to reconfigure their worlds and arbitrate conflict-ridden situations or moral tensions arising from the misfortune that might befall individuals (Ehrenberg 2014; Moutaud 2011).

These patients are well known in the literature on DBS and became subjects of sociological (Gisquet 2008), anthropological (Moutaud 2011) and ethical concerns (e.g. Gilbert 2012), and have additionally led physicians to assess patients' (and their relatives') experiences of the therapeutics (e.g. Ferrara et al. 2010; Soileau 2014). But above all, together with patients affected by disabling side effects (and, it has to be noted, sometimes the two situations are difficult for physicians to distinguish), they put to the test the organization of care and its effectiveness. The team had to adapt its structure to the complexity of the clinical and personal situations generated by the technology. They reorganized modes of care provision, yielding complex organizational patterns and large numbers of different staff involved (psychiatrists, psychologists, social workers, support groups, therapeutic education, new neurological consultations, etc.), taking into account the necessary continuity of care for life-long follow-up. This increased organizational complexity has consequences on the modes

of regulation and diffusion of this technology as a routine practice, especially given its cost (equipment and follow-up). Thus, while in France the technology has taken over from ablative procedures (lesional surgery) in psychiatry and neurology (the reimbursement of DBS for Parkinson's disease by the French national health insurance was authorized in 2005), in some other countries the question has been raised as to whether there should be a return to these previous approaches in view of complaints from patients and the problems they encounter adapting to the effects of stimulation that could prove to be too demanding on clinicians' time (Rabins et al. 2009). Due to the scarcity of centers able to provide DBS and to the cost of this technology, particularly for patients in countries where there is no universal health care, lesional surgery has proven easier to provide, despite its irreversible consequences and side effects (see, e.g. Eskandar 2003).<sup>11</sup> As a result, the problems raised by the regulation of the experimental bodies and 'unsatisfied' patients and the way they are produced highlight the challenges of the rationalization of care provision for patients under stimulation. For many observers, what is at stake is the actual survival of the technique.

## CONCLUSION

In this article, I have cast light on the different forms of practice that structure and promote the development and circulation of a technology for the treatment of psychiatric and neurological disorders. I have described how researchers, physicians and patients may divert the use of DBS from its therapeutic objective as a technology to explore the functioning of the human brain, or as a technology of self-enhancement. These diversions of DBS can coexist in time and space and contribute both to accelerating and to slowing down its circulation, stimulating interest or jeopardizing its future. Depending on situations, discourses and actors, DBS, as a powerful technology to produce knowledge and as a potential therapeutic approach for a large

number of conditions, is offering a new dynamic for the neuroscience project by conflating research and the clinic, the care of patients with experimentation in a neuropsychiatric agenda.

At the same time, this neuromodulation technology appears as an empirical manifestation of the profound reconfigurations imposed by neuroscience on human beings, raising questions about the regulation of the bodies and new personal and biological identities that are produced. DBS is opening up a field of practice where we can question the frontiers of human life, and reappraise the ways we can ethically manipulate living beings, transforming individuals. These new possibilities are apparent in my description of the way implanted patients use DBS as a new model of causality, a new manner to redefine the links between their biological existence and their relational life. This neuro-technology provides them with a new language to assert control over their lives and produce a new form of life.

Standing at the crossroads of various clinical or research specialties, the circulation and regulation of DBS applications in neurology and psychiatry raise scientific, ethical, and social issues that are as wide-ranging as the plurality and entanglement of human ontologies that are shaped in its practice. DBS is too powerful and hybrid to be frozen and confined to internalist histories or imaginary narratives that ignore both the complexity of the situations produced and the different interests at stake. The question of the viability of DBS implementation as routine practice in hospital wards and national healthcare systems highlights the complexity of establishing its nature as a therapeutic technology (e.g. what it can or cannot do) and the means and goals enabling its standardization. Diffusion and circulation of neuromodulation technologies (or the lack of diffusion for some of them) correlate with ethical issues but also with institutional, industrial, financial, and structural factors that raise the question of disparities in clinical and technical skills. Tracking these moving targets still requires precise and systematic investigation.



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## NOTES

1. The US Food and Drug Administration approved DBS as a treatment for essential tremor in 1997 and Parkinson's disease in 2002. DBS device received a license for the use in the European Union in 1998. See Gardner (2013) about the history of DBS scientific regulation and the role of industry; Talan (2009) for a well-documented history of the early development of DBS.

2. To give an idea, a search on PubMed with the term 'Deep Brain Stimulation' (title/abstract) shows that between 2000 and 2013 the volume of publications increased tenfold, to a total of over 5000 articles.

3. <http://www.medtronic.com/patients/parkinsons-disease/therapy/benefits-and-risks/index.htm>

4. For instance, the United States Federal Defense Advanced Research Projects Agency released a budget of US \$70 million over five years at the end of 2013 for DBS research (Gorman 2013).

5. The word 'neuromodulation' refers to a heterogeneous set of invasive or non-invasive technologies (DBS, magnetic transcranial stimulation, electroconvulsive therapy and vagus nerve stimulation) allowing researchers and clinicians to electrically modulate brain

functions. If the use of DBS is not the most widespread, it has a larger spectrum of therapeutic applications in neurology and psychiatry.

6. My translation. The English title provided by Benabid to the French journal is: “The return of psychosurgery.”

7. Although such wards are scarce and thus probably easily identified, all names have been changed to preserve anonymity, as it was agreed upon at the outset of research.

8. In psychiatry, hypomania refers to cases of elated mood leading to behaviors perceived as eccentric, and unlike the person's usual manner. The individual concerned is agitated, elated, sleeps little, talks incessantly and behaves impulsively or even aggressively.

9. See, for instance, the editorial by the psychiatrist Mayberg and the neurosurgeon Lozano (2002), two major figures in DBS, where the reference to Penfield is not explained in the text.

10. Especially in surgery, where practices are difficult to standardize (Schlich 2007). The success of the procedure rests not only on surgical skills but also on the technical resources of the surgical teams (targeting technologies, brain atlases, etc.).

11. See, for instance, the recent controversy opened by a neurosurgeon who alerted the scientific community about the ethical, medical, and scientific concerns about a Mexican team which published ten cases of patients treated for ‘aggressive behavior’ with lesional surgery (Lévêque, Weil and Régis 2013). While DBS was discussed as a ‘reversible’ and ‘less harmful’ therapeutic option, the Mexican psychiatrist in charge of these patients pointed out that families cannot afford such an expensive procedure (he evaluated the cost of DBS as approximately between US \$55,000 and 70,000 versus US \$500 for lesional surgery) (Cabut and Saliba 2013).

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