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# A Personal Narrative on Living and Dealing with Psychiatric Symptoms after DBS Surgery

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**Abstract.** Although deep brain stimulation (DBS) may result in dramatic motor improvement in people with Parkinson's disease (PD), it has been correlated with a number of postoperative psychiatric side effects. We report a case of a person with PD experiencing depression and hypomania following DBS surgery. We provide a detailed report of the patient's personal experiences dealing with and managing these psychiatric side effects for three years. Providing a personal narrative focusing on detailed patient subjective experiences complements reports that give insight into the short- and long-term effects of DBS on established psychiatric measures and neurologic activity. But, most importantly, such a qualitative approach provides prospective patients and clinicians with a broader ethical picture of real-life challenges faced and coping strategies employed by PD patients treated with DBS who are experiencing psychiatric adverse events. This case study reinforces the ethical need to disclose the potential risk of harm to prospective patients as well as the importance of establishing a multidisciplinary postoperative supportive group.

**Keywords.** Deep Brain Stimulation, Identity, Neuropsychiatric Effects, Parkinson's Disease, Self, Side Effects.

## Introduction

Deep brain stimulation (DBS) has been regarded as an efficient and safe treatment for Parkinson's disease (PD) for the last 25 years (Schultz, 2002). During this time, several thousands of people with PD have received DBS therapy. In terms of clinical

ethics, it is worth asking whether the use of DBS may have unanticipated negative effects similar to those associated with other types of neurosurgery: in particular, how postoperative neuropsychiatric effects may impact upon a patient's sense of self (Gilbert, Cook, O'Brien, & Illes, 2017; Gilbert,

Goddard, Viaña, Carter, & Horne, 2017; Gilbert, Vranic, 2015; Gilbert, Harris, Kapsa, 2014). In some instances, symptoms are alleviated but patients do not cope well with their new “normal” life, a syndrome known as the “burden of normality” (Gilbert, 2012).

Potential adverse effects of DBS raise important ethical concerns. Unlike the side effects of drugs that may simply require stoppage of intake or decrease of dosage to be controlled, DBS is an invasive procedure that necessitates risky interventions for removal from the body. Most importantly, turning stimulation down may not actually alleviate side effects; indeed, studies have shown that calibrating stimulation has induced worst adverse effects for some patients, including suicide attempts (Gilbert, 2013a; 2015a). As a result, DBS adverse events may increase the magnitude of harm to patients, especially if the intervention appears to be correlated with postoperative effects involving the core components of a patient’s personality: self and identity.

The phenomenological effects of DBS on patients’ postoperative existence remain poorly understood. Some researchers suggest that the impact of DBS on patient personality is characterized by self-perception through narrative identity (Focquaert & De Ridder, 2009); changes in thought and personality (Glannon, 2009); disruptions of psychological continuity influencing competence and responsibility (Klaming & Haselager, 2010); alteration of a patient’s core attitudes (Witt, Kuhn, Timmerman, Zurowski, & Woopen, 2013); variation in embodied, affective, intersubjective, cognitive, narrative, extended, and situated aspects of the self (Dings & de Bruin, 2016); or changes in relational autonomy competences (Brown et al., 2016). We do not have enough space to characterize all accounts adequately, but it appears that DBS may lead to some existential side effects that are ostensibly profound, as patients may experience shifts in identity in relationship to both themselves and their families.

Most studies on the psychiatric adverse events caused by DBS in PD patients focus on its effect on several established psychological tests and

psychiatric measures in a number of individuals over time (Castrìoto, Lhommée, Moro, & Krack, 2014; Boel et al., 2016), with a few investigating the effect of stimulation on brain activity (Ulla et al., 2011). Although some publications present case reports, providing brief descriptions of the progression of the experienced psychiatric symptoms with respect to adjustments in medication and stimulation parameters (Funkiewiez et al., 2004; Rodrigues et al., 2010; Ugurlu, Acar, Karadag, & Acar, 2014; Widge et al., 2013), or statements from patients and caregivers (Lewis et al., 2015), they do not really provide detailed long-term information on patients’ subjective experiences before symptom onset and potential socioenvironmental factors that could have triggered or exacerbated these symptoms, patient perspectives while experiencing psychiatric conditions, and coping strategies that patients potentially employ in addition to medication and stimulation adjustments. This presents a gap in the literature on DBS-associated psychiatric adverse events from patients’ points of view, information that that would also be important in understanding how these events affect actual patient day-to-day experiences and perceptions of DBS therapy.

In this study, we report on the case of a patient with PD exhibiting depression and hypomania after DBS, despite improvement in motor symptoms. We detail the patient’s personal experiences with these psychiatric adverse events and the ways in which she experienced them. These qualitative accounts provide a perspective beyond standard psychological tests, psychiatric evaluations, and neurologic measurements on neuropsychiatric issues in DBS for PD by highlighting a PD patient’s perception of life with these symptoms and providing prospective patients and clinicians a more detailed, relatable, and empathic understanding of these issues through the narration of our case subject’s experiences of struggle, acceptance, and recovery. This case illustrates an ethical concern, in that successful postoperative alleviation of motor symptoms did not necessarily result in an improvement in the patient’s overall well-being.

## Case Report

A 46-year-old female patient, with no history of mental health issues, underwent bilateral subthalamic nucleus (STN) DBS in August 2013. She consented to DBS surgery 6 years after receiving a diagnosis of PD and being refractory to the most common drugs (dopamine agonists). Following DBS surgery, Parkinsonian tremor remained substantial, which required adjustment of stimulation parameters. Calibration resulted in significant diminution of motor symptoms; however, concomitant psychiatric symptoms emerged, in particular depression and mania, for which Zoloft and Seroquel were prescribed. In the following months, the patient experienced a wide range of feelings, especially intense distress, which were articulated through various narratives. Subsequently, her therapeutic relationship with her neurologist and surgical team broke down. Successively, she divorced the father of her children, moved to another state, and ultimately attempted suicide in February 2014.

The patient was included in our multicentre qualitative postoperative study of DBS for PD. We used qualitative methodological tools to conduct continuous in-depth, semistructured interviews using open-ended questions in order to understand PD patients' perception of self-changes following surgery (Gilbert, Goddard, Viaña, et al., 2017). This qualitative approach gave us access to first-person perspectives that are not captured by standardized questionnaires and scales.

The patient reported a persistent state of self-perceived changes following implantation. More than one year after surgery, her narratives explicitly refer to a persistent perception of strangeness and alteration of her concept of self. For instance, she reported:

can't be the real me anymore—I can't pretend . . . I think that I felt that the person that I have been [since the intervention] was somehow observing somebody else, but it wasn't me. . . . I feel like I am who I am now. But it's not the me that went into the surgery that time. . . . My family say they grieve for the old [me]. . . .

In another occurrence, when discussing her divorce and the rupture in her familial structure, she

reported how her children perceived her postoperative self:

*Patient:* My family say they grieve for the old [me] . . .

*Interviewer:* What have your children said to you about the difference that they've seen before and after?

*Patient:* Yes, they said they don't recognize me.

*Interviewer:* And in what way don't they recognize you?

*Patient:* That I am so impulsive and seem to change my mind all the time. . . .

The patient also reported developing severe postoperative impulsivity: "I cannot control the impulse to go off if I'm angry." In parallel, while describing a sense of loss of control over some impulses, she has also recognized that DBS gave her increased feelings of strength: "I never had felt this lack of power or this giving of power—until I had deep brain stimulation." Here, the patient's "lack of power" in some aspects of her character seems to also result in a "giving of power" in other novel qualitative features of character; that is, a loss of control leading to a disinhibition has also given her some incommensurable feelings of strength. For instance, she experienced radically enhanced capacities, in the form of increased uncontrollable sexual urges:

I know this is a bit embarrassing. But I had 35 staples in my head, and we made love in the hospital bathroom and that wasn't just me. It was just I had felt more sexual with the surgery than without.

And greater physical energy:

I remember about a week after the surgery, I still had the 35 staples in my head and I was just starting to enter the cooler months of winter but my kids had got me winter clothes so I had nothing to wear to the follow up appointment and when I went back there of the morning, I thought "I can walk into the doctor's" even though it was 5 kilometers into town. It's like the psychologist said: "For a woman who had a very invasive brain surgery 9 days ago and you've just almost walked 10 kilometers." And on the way, I stopped and bought a very uncharacteristic dress, backless—completely different to what I usually do.



Figure 1. A colored painting made by the patient.

In the following interviews, the patient's experience of being estranged from her previous self was different; in particular, when the treating psychiatrist tried calibrating the DBS parameters:

I went to the psychiatrist, and he said, "Right, well, this is bordering on mania, you need to turn the settings right down to manage it." I said to him, "Please don't, this is not over the top—this is just joy."

Eventually, the patient's narrative started to indicate progressive coping with postoperative psychiatric changes:

Well, it was different to—I've always been a worrier for so many years. Now, I don't seem

to have that worry thing anymore . . . I feel that other [me] that was before the surgery would never have able to stand on her own two feet. . . . I wouldn't [have] been able to cope if I was the old [me]."

To some extent, the patient started to use her new postoperative capacities. She started expressing her emotion through colored painting (Figure 1) and is currently selling some of her creations.

I don't know, all the senses came alive. I wanted to listen to Paul Kelly and all of my favorite music really loud in the toilet. And you know, also everything was colourful. . . . Well, since brain surgery I can. I didn't bother before. I can see the light . . . the light that is underlying



every masterpiece in photography. . . . I've seen it like I've never seen it before . . . I am a totally different person. I like it that I love photography and music and colourful clothes, but where is the old me now?

The patient still faces challenges linked to her new self, but she has developed an attitude to embrace several aspects of it:

*Interviewer:* And over this subsequent 2 years, you've come to actually feel that rather than being self-estranged, you are actually truly who you are—is that correct?

*Patient:* Yes.

*Interviewer:* Would you go back to the old [you] if you could?

*Patient:* No. . . . I don't have any regrets about who I am now. But I have regrets, and I'm not angry anymore—just concerned that I wasn't given the opportunity to know what could possibly happen.

A surprising element we observed is that on many occasions, the patient mentioned and maintained that she was never informed by her initial medical team about potential unwanted psychosocial effects of the treatment.<sup>1</sup>

## Discussion

There is an ongoing debate in the literature about the clinical and ethical implications of personality changes following DBS surgery. This debate discusses trade-offs between the motor benefits of DBS and the potential psychological harm caused by the intervention. The discussion often addresses the issues of how the medical team should account for personality changes (de Haan, Rietveld, Stokhof, & Denys, 2013), whether patients should be prescribed deactivation or explantation (Gilbert, 2015a), and what moral criteria could guide a patient's decision to accept side effects while enjoying motor symptom alleviation (Glannon, 2009). Our case

raises ethical difficulties because it illustrates how DBS treatment may result in unexpected outcomes for patients along with a diminution of targeted symptoms, even after many years of follow-up. As a result, the ethical question of benefits and risks associated with DBS treatment is raised. The potential psychosocial risks demonstrate that access to information with respect to potential unwanted DBS-induced effects is an ethical priority. Clinicians should prioritize appropriately informing prospective patients, their families, and their caregivers about treatment responses that might not be in line with the therapeutic goals of the DBS intervention. Access to information should also highlight the limits of the treatment and its potential long-term psychosocial effects, despite diminution of the illness's core symptoms. It is fundamental to stress these details, as our patient reported never having received information on potential unwanted psychosocial effects of the treatment from her initial medical team.

The observed psychiatric side effects in the case reported here are not the first of their kind and have also been observed in other PD patients who underwent STN DBS. Depression (Anderson & Mullins, 2003), mania (Ugurlu et al., 2014; Chopra et al., 2012), aggression (Sensi et al., 2004), and impulsivity (Hälbig et al., 2009; Ballanger et al., 2009) have all been observed in a number of patients. Such effects can be due to the stimulation itself or accompanying medication changes and can also be influenced by preoperative psychiatric history (Anderson & Mullins, 2003; Witt, Daniels, & Volkmann, 2012). Moreover, the postoperative development or progression of these psychiatric side effects varies, with some patients reporting improvement and others worsening (Castrioto et al., 2014; Anderson & Mullins, 2003; Couto, Monteiro, Oliveira, Lunet, & Massano, 2014). Following STN DBS, some patients become less depressed while others become more so (Funkiewiez et al., 2004; Couto et al., 2014), with some having suicidal ideations or even committing suicide despite motor improvements (Weintraub et al., 2013; Rodrigues et al., 2010). The reduction of dopaminergic drugs in PD patients receiving DBS might lead to dopamine withdrawal syndrome,

<sup>1</sup>The patient has taken legal action against the lead neurosurgeon. Legal procedures were still in progress at the time this article was written.

which could cause depression (Castrियो et al., 2014; Thobois et al., 2010). The ethical concern is how to balance motor improvement with these effects, especially if they seem irreversible.

Our patient experienced depression and eventually attempted suicide, which could have been precipitated by persistent feelings of distress and the breaking down of her relationships with her physicians and ex-husband. The severity of these side effects emphasizes the importance of long-term narrative studies in PD patients receiving DBS in determining how postoperative mood changes affect patients' quality of life, understanding how depressed patients see treatment effects and might feel unsatisfied despite motor improvements, and identifying potential social and environmental factors that could affect postoperative depressive feelings and precipitate suicidal ideations and attempts (Gilbert, 2012; 2013b).

The first-person narrative presented in this study aims to highlight experiences of mania and hypersexuality from a patient's perspective rather than from an external observer's evaluation and to demonstrate the patient's thoughts and feelings when these tendencies and symptoms emerge. These subjective reports are ethically fundamental to making sense of drastic changes that may harm the patient: in particular, negatively affecting what constitutes first-person experiences. By exploring the patient's subjective experience of being implanted, we examine what makes a person who she is: the subject of her own experience—unique and distinct from that of any other subject (Gilbert, 2017). The patient claimed that “I can't be the real me anymore—I can't pretend . . . I think that I felt that the person that I have been [since the intervention] was somehow observing somebody else, but it wasn't me,” and “I feel like I am who I am now. But it's not the *me* that went into the surgery that time.” These feelings reflect a notion of self-estrangement: in other terms, being the estranged subject of experiences; “estrangement of the self from itself” (Gilbert, 2017). The ethical issue with self-estrangement is that it can be associated with deteriorative aspects (e.g., depressive symptoms) and restorative aspects (e.g., distorted perception

of capacities) (Gilbert, Goddard, Viaña et al., 2017). In either case, patients may not cope well with these newly acquired aspects.

The patient's narratives of deteriorative estrangement appear to be compatible with previous literature reporting an increased number of patients perceiving themselves as having an altered or different personal identity following DBS, despite motor improvements. Previous studies have reported patients experiencing feelings of strangeness, including narratives such as the following: “I don't seem to recognize myself without the problems I had before” (Agid et al., 2006) and “I don't recognize myself anymore; I haven't found myself again after the operation” (Schüpbach et al., 2006). Previous studies have highlighted the salient issue that patients suffering from deteriorative self-estrangement were at greater risk of harm, including from suicide attempts (Gilbert, 2015a; 2013a).

Exploring patients' feelings of self-estrangement allows us to comprehend which cognitive, affective, and conative capacities may have been drastically affected, and, as a result, compromise their ability to freely act or make decisions. For instance, our patient reported feeling “more sexual with the surgery than without,” leading her to manifest degrees of hypersexuality.<sup>2</sup> The general increase in her sexual arousal and activity, tangential with augmented impulsivity, may call into question whether she is ultimately responsible for some of her behaviors and actions: “I never had felt this lack of power or this giving of power—until I had deep brain stimulation.” These first-person experiences have indicated how the patient is aware that her behavior is different from her pre-DBS self and that the hypersexual person post-DBS is questioning who she has become. This is very

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<sup>2</sup> Although reports of increased sexuality immediately after DBS surgery and after initial stimulation (Romito & Albanese, 2010) and of impulsive actions as a result of feelings of grandiosity and energy increase have been presented before (Ugurlu et al., 2014), they have not really highlighted a patient's feelings during these episodes.

important, because it could assist the medical team in (re)evaluating the harmful outcomes that have occurred despite successfully addressing therapeutic endpoints. For instance, when the psychiatrist recommended that “. . . you need to turn the settings right down to manage it,” the patient replied, “Please don’t, this is not over the top—this is just joy.” These dilemmas echo how a patient might prefer to keep a particular stimulation parameter because of feelings, such as joy, that DBS induces (Chattha, Greene, & Ramdhani, 2015; Krack et al., 2001). However, practitioners’ responses to patient requests to operate stimulation at a certain level should always take into account the risk of harm.

As discussed, what characterizes the reported patient’s potential postoperative harmful experience, as in other cases (Gilbert, Goddard, Viaña et al., 2017; Agid et al., 2006; Schüpbach et al., 2006), can be understood by way of deteriorative estranged effects. We believe that the patient substantially experienced deteriorative estrangement correlated with a radical and ongoing sense of loss of control over some important capacities, which reflects an involuntary and unintentional shift in her character: to some extent, a “radical disruptive experience which redefines the patient’s life” (Gisquet, 2008). These capacities were implicated in her conception of herself as a rational agent, able to decide and freely choose what is in her best interest. Her struggles with postoperative estrangement, especially to reidentify with particular qualitative capacities, through activities, emotions, and aspirations, illustrate a loss of control of some elements of herself. As such, the case report appears to further corroborate the hypothesis that postoperative self-estrangement experiences seem to qualitatively characterize the notion of powerlessness (Gilbert, 2013a), which is often manifested through involuntary self-harming actions or behaviors or loss of control.

The patient went through a spectrum of subjective experiences, articulated in various narratives, from intense distress (suicide attempt) to manifestations of stability (little regret for her previous self). Along the spectrum of feelings associated with self-interpretation of strangeness, the patient reported

subjective changes in her capacities. Some of the testimonials show that she initially experienced DBS-induced capacities as not representative or characteristic of herself. This experience of a gap in character has been felt in many cases as a malaise (Gilbert, 2017). In some instances, this malaise took the form of a dispossession of control of some capacities. In this case, such malaise appears to antagonize the patient’s ability to appropriate her new capacities. The existence of sudden and persistent capacities that are not embraced by the patient following stimulation is evidence that a different subjective experience of the self has emerged poststimulation. Self-estrangement reflects the idea that feelings of strangeness reach a critical proportion when DBS-induced capacities overpower previous capacities and specific behaviors (Gilbert, 2017). Some aspects of this postoperative overtaking can be negative, as in cases where the patient becomes impulsive. However, not all situations would appear to be negative, as seen with the implanted patient in this case study who enjoyed new sexual capacities and developed artistic ways of expressing herself.

Eventually, the patient managed to come to terms with her newfound self and interests while still being aware that she was no longer her old self. These phenomenological accounts can help the medical team address some issues: in particular, by illustrating variance between the experiences of different subjects, such as affective valence and intensity (Bittlinger, 2017). This could help guide medical decisions to remove, deactivate, or maintain treatment. Understanding nontargeted effects of this therapeutic intervention will better prepare PD patients and physicians for potential side effects of a more interpersonal nature.

Overall, our case illustrates the lack of acknowledgment by this patient’s initial medical team concerning the existential dimensions of her postoperative experience. These dimensions translate into three main ethical issues: (1) A patient might prefer not to be implanted with DBS knowing that these changes could occur. However, should the risk be deemed acceptable, then (2) there may be a way to design a better shared decision-making process, involving the patient’s family, in order to prepare



everyone for possible identity and personality shifts. Should this process lead to fair negotiation between the patient and his or her family, then (3) all of them must consent to accepting the potential long-term unanticipated harmful consequences (patient: being symptom-free but potentially becoming an unexpected “new” person; family: living with a treated but perhaps unwelcome “new” person). The first issue appears to be a sole and ultimate decision made by the patient that aims to preserve patient sovereignty within his or her entourage. The second issue involves an acceptance of the potential risk, but includes preparatory phases to help the patient and his or her family manage possible unwanted outcomes.<sup>3</sup> The third issue addresses the possibility of adverse outcomes experienced by the patient that are incompatible with her or his family values and expectations. These possible ethical issues reflect the need for patients and families to face existential adversities (including potential psychiatric side effects) that may accompany the alleviation of the patient’s motor symptoms.

## Conclusions

In this report, we present the narrative of a patient who experienced depression, mania, impulsivity, hypersexuality, and self-estrangement after DBS. Such a narrative can provide support to patients experiencing these unexpected postoperative neuropsychiatric effects, prepare caregivers to deal with potential neuropsychiatric consequences, educate family members about potential sudden behavioral changes, and generate knowledge that could guide prospective patients and their families through the decision-making process leading to

implantation. For patients and families, knowing that postoperative neuropsychiatric changes are also experienced by several individuals undergoing DBS treatment could help them understand and appreciate the difficulties caused by these side effects and potentially motivate them to establish or join patient support groups. Finally, this case study illustrates that the perspectives and narratives of patients facing postoperative neuropsychiatric changes and self-estrangement should also be given importance in devising management strategies not only for the motor symptoms of Parkinson’s disease but also for the range of non-motor symptoms that are the adverse effects of medication and stimulation.

The narrative approach that we used in describing patient experiences post-DBS sheds an additional light on the procedure’s psychiatric effects, demonstrating the need to support patients’ postoperative trajectory with a multidisciplinary team. Narrative medicine, especially in psychiatry, facilitates better understanding of patients’ experiences, encourages patient participation in illness reporting, and helps align scientific and medical knowledge with specific patient symptoms, needs, and preferences (Holmes, 2000; Schultz & Flasher, 2011). In addition, patient narratives are important tools in informing the public about the disorder by revealing the human side of illnesses (Sachdev, 2011). In this report, the use of a narrative approach sheds light on how feelings of self-estrangement initially caused distress to the patient but eventually led to acceptance and coping. It highlights the importance of not just resolving the motor condition of PD patients but also addressing non-motor symptoms that might arise from treatment. Finally, it makes descriptions of adverse side effects more relatable to future patients and caregivers and gives them a more personal insight on problems and issues, beyond the medical diagnosis of psychiatric conditions, that they might face post-DBS.

As novel implantable brain technologies are developing fast—for instance, in their control by artificial intelligence to target neurological and psychiatric conditions—new ethical issues will likely emerge (Gilbert, Cook, O’Brien, & Illes, 2017;

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<sup>3</sup> *Patient postoperative socioenvironmental trajectory is compatible with previous studies reporting postoperative changes associated with family dynamics and restructuring. For instance, “64% of patients who were working before surgery wanted to stop their professional activity, and 65% of those who were married (or lived with a partner) experienced a conjugal crisis after operation” (Agid et al., 2006, p. 410).*

Reardon, 2017; Gilbert, 2015b; Gilbert, Cook, 2015; Gilbert, O'Brien, Cook, 2018). As our case study has demonstrated, keeping in mind the possibility that novel neurotechnologies may have profound existential side effects will be critical for ensuring patients' wellness.

## Ethics Approval

This study was conducted in accordance with Tasmanian Human Research Ethics Committee regulations. Patient consent and minimal risk ethics application approval, entitled "H0014820 Deep Brain Stimulation Postoperative Suicidal Ideation within Treatment Resistant Depression: Why Removing the Devices is Not Enough," conform to Tasmanian Human Research Ethics Committee regulations. Ethics approval was obtained in 2015. The patient provided consent to have her narratives included in publications on neuropsychiatric side effects of DBS for PD.

## Discussion Questions

1. What obligations do DBS providers and researchers have to offer follow-up care aimed at addressing potential personality and behavior changes that can cause patients distress?
2. What are the trade-offs between the motor benefits of DBS and the potential psychological harm induced by treatments?  
Should decision aids be developed to help patients weigh the pros and cons? What would you put into such a decision aid?
3. Should family members have a greater voice in DBS decision-making than in ordinary healthcare decision-making given the potential impact of DBS on personality and behavior?

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