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Target Article

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I Miss Being Me: Phenomenological Effects of Deep Brain Stimulation

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The phenomenological effects of deep brain stimulation (DBS) on the self of the patient remains poorly understood and under described in the literature, despite growing evidence that a significant number of patients experience postoperative neuropsychiatric changes. To address this lack of phenomenological evidence, we conducted in-depth, semistructured interviews with 17 patients with Parkinson's disease who had undergone DBS. Exploring the subjective character specific to patients' experience of being implanted gives empirical and conceptual understanding of the potential phenomenon of DBS-induced self-estrangement. Our study concluded that (1) the more patients preoperatively felt alienated by their illness, the more they experienced postoperative self-estrangement, and (2) the notion of self-estrangement seems to exist in association with certain common qualitative characters, namely, loss of control, which reflects a deteriorative estrangement, and distorted perception of capacities, which reveals a restorative estrangement. These findings indicate that subjective self-reports help us to understand some aspects of the potential phenomenon of DBS-induced self-estrangement.

Keywords: alienation, deep brain stimulation, distorted perception, loss of control, Parkinson's disease, self, side effects, self-estrangement

Despite growing evidence that a significant number of patients experience postoperative neuropsychiatric changes (Volkmann, Daniels, and Witt 2010; Muller and Christen 2011, Clausen 2010), including reports of irreversible alteration following removal of implants (Gilbert 2013a), the phenomenological effects of deep brain stimulation (DBS) on the patient's self remain poorly understood and underdescribed in the literature. Most postoperative reports emerging from clinical studies measure standard cognitive, psychometric, and functional scales (Smeding et al. 2011; Lewis et al. 2015; Pham et al. 2015; Schoenberg et al. 2015). Most discussion of the postoperative changes following the implantation of brain devices such as DBS focuses on abnormal side effects caused by the intervention (e.g., hypersexuality, hypomania). By contrast, relatively little attention is paid to the idea that successfully "treated" individuals might experience difficulties in adjusting to becoming "symptom free": a phenomenon that is known as the "burden of normality" and that can lead to postoperative iatrogenic harms (Gilbert 2012; Wilson, Bladin, and Saling 2007). The risk of postoperative iatrogenic harms can be extremely serious; in a statistically significant number of clinical trials, implanted patients have attempted or died by suicide (neurological condition: Temel et al. 2009; psychiatric condition: Gilbert 2013a; Gilbert 2013b). Given the failure of studies to faithfully capture patients' experience of a "new" postoperative self, potential DBS-induced phenomenological effects on patients' self remain largely unexplored. DBS's nontarget effects and their impact on patients' self are particularly concerning, given the number of patients being implanted for approved therapy (more' than 100,000) and the increasing number enrolled in experimental trials (Medtronic 2013).

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To our knowledge, only a small number of studies in the literature have specifically addressed the phenomenology of the self through a patient's subjective experience with DBS (de Haan et al. 2015; de Haan et al. 2013, Hariz et al. 2011, Schüpbach et al. 2006). A small number of case reports provide further insight into some of these postoperative changes to the self. With so few phenomenological investigations into the experience of self, the philosophical debates about potential postoperative effects of DBS on the self are mostly based on anecdotal cases that may not be representative, but are used to serve authors' arguments. It is essential to supplement the current literature with more rigorous empirical studies exploring the phenomenological effects of DBS on the self. Studying patient's first-personal experience of DBS through the unique phenomenological lens to explore patient's self-perception will shed light on current philosophical disputes, but most importantly, will guide prospective patients through decision-making processes leading to implantation.

To address this lack of phenomenological evidence, we conducted in-depth, semistructured interviews using open-ended questions with 17 patients with Parkinson's disease (PD) implanted with DBS in Australia, from the states of Victoria, Tasmania, and Queensland.[1] The average duration of the interviews was 45 minutes. This qualitative approach allowed us to capture first-personal perspectives that are not identified by standardized questionnaires and scales. Three independent researchers conducted the interviews and transcribed the content. All interviews were conducted in English. Interviews were analyzed by grouping patients' self-experience into four main phenomenological clusters of experience: (1) degrees of alienation caused by PD or benefit caused by PD; (2) postoperative feelings of enablement or powerlessness; (3) postoperative feelings of embodiment or disembodiment; and (4) reports of postoperative changes by partner/family members. These clusters were then divided by subthemes, which were populated by patients' key answers and quotes. Table 1 reports patients' details, and Appendix 1 is the semi-structured questionnaire used to guide our interviews. Our aim was to explore perceptions of self-change by patients implanted with DBS. As this is a qualitative study based on first-personal narratives involving more than 765 minutes of interviews, the results are highlighted and given in excerpt format.

This article (1) reports our general findings; (2) reports and discusses findings related to deteriorative and restorative self-estrangement; (3) discusses embodiment through patients' accounts of experiencing DBS implants as being part of them; (4) summarizes the notion of self-estrangement; (5) advocates that DBS alone does not directly causes potential self-estrangement; (6) indicates some limits of our research; and (7) provides general conclusions from our collected data.

PATIENT SUBJECTIVE ACCOUNTS: EXPERIENCING SELF-ESTRANGEMENT

Before reporting our results, we need to define some terminology. Exploring the phenomenon of DBS postoperative self-estrangement involves an examination of whether experiencing self-estrangement involves certain qualitative experiences as phenomenally characterized by implanted patients. From a phenomenological perspective, if we define the self as, broadly construed, the subject of one's phenomenological experience of X (e.g., X being an emotion, perception, thought, etc.), then we understand that the very existence of some particular phenomenological experiences can qualitatively reflect the self. By experience, as Strawson formulated it, we understand experiential "what-it's-likeness" (Strawson 2011).[2] The existence of a self qualitatively experiencing X is given with the existence of experiencing X. In other words, experiencing DBS likely entails specific or common qualitative experiences; we aimed to explore these specific or common DBS-related experiences, especially any experiences of estrangement. By looking at the subjective character specific to patients' experience of being implanted, especially through phenomenological experience of first-personal or subjective change, we believe we can gain better empirical and conceptual understanding of the phenomenology of potential DBS-induced self-estrangement.

Our study reveals that there is a strong correlation between postoperative estrangement and how patients preoperatively perceive themselves with respect to their illness. In other words, 100% of patients who perceived PD as not intruding on their life did not experience feelings of estrangement ($n = 4$). For instance, Patient 08 and Patient 12 clearly articulated this correlation:

> Patient 08: "The disease is part of me. You can't separate from the disease" and "I don't think [DBS] changed me, it hasn't changed my personality or who I am, or how I feel about myself."
>
> Patient 12: "[Parkinson's] is not a painful experience . . . I was able to do things and contribute to society in ways I would otherwise have been unable to do" and later pointed out that "[DBS] has not changed who I am, it's improved."

1. This study was conducted in accordance with the Tasmanian Human Research Ethics Committee regulations. Patient Consent and Minimal Risk Ethics Application Approval, entitled "H0014820 Deep Brain Stimulation and Postoperative Self-Adjustment Phenomenon," are also in compliance with the Tasmanian Human Research Ethics Committee regulations. Ethical approval was obtained in May 2015.

2. We draw on Strawson's account here in order to justify looking at the subjective experience of DBS implantation. We do recognize, however, that this is a "thin" account of the self and that Strawson's conception of phenomenology can be contrasted with a "thick" account, which takes agency and embodiment as defining of the phenomenological standpoint.

Table 1. Patients' general information.

Patient	Age (surgery)	Gender	Time span between surgery and interview	Time span between PD diagnostic and surgery
P01	64 years old	F	1 year 6 months	10 years
P02	68 years old	F	1 year	20 years
P03	68 years old	M	2 years 2 months	12 years
P04	52 years old*	F	1 year 2 months	6 years
P05	82 years old	F	3 years	12 years
P06	63 years old	M	1 year	8 years
P07	53 years old	F	4 years	9 years
P08	50 years old	M	6 years	9 years
P09	54 years old*	F	5 years	16 years
P10	58 years old	M	1 year	11 years
P11	50 years old	M	6 years	10 years
P12	66 years old	M	1 year	11 years
P13	66 years old	M	2 years	6 years
P14	40 years old	M	4 years	7 years
P15	69 years old	M	4 years	19 years
P16	**	F	3 years 6 months	**
P17	52 years old	M	5 years	8 years

*Patients had two surgeries. Patients' ages during the second surgery.
**Was not provided.

In parallel with this strong correlation between preoperative perception of oneself through disease and a sense of estrangement, we observed that patients (61%) who felt alienated by their illness were likely to experience, to various degrees and intermittently, some postoperative feelings of self-estrangement ($n = 8$). For example:

> Patient 16: "[Parkinson's disease] really takes over. . . . I couldn't work which was a big part of my identity. . . . If I didn't have the device I'd probably be dead right now" and later states "I think that [DBS] does change you as a person."

Our findings indicate that the more patients preoperatively felt alienated by their illness, the more they experienced postoperative self-estrangement. The question that needs to be addressed in the next section is how experiencing DBS self-estrangement correlates with some specific qualitative character common to some implanted patients.[3]

EXPERIENCING DETERIORATIVE AND RESTORATIVE SELF-ESTRANGEMENT

Our study found that postoperative self-estrangement could be phenomenally experienced as deteriorative or restorative by implanted patients. Deteriorative or restorative self-estrangement involves experiencing an involuntary shift in the qualitative character. For instance:

> Patient 04: "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. . . . 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] . . ..
>
> Interviewer 2: "What have your children said to you about the difference that they've seen before and after?"
>
> Patient 04: "Yes, they said they don't recognize me."
>
> Interviewer 2: "And in what way don't they recognize you?"
>
> Patient 04: "That I am so impulsive and seem to change my mind all the time."

What characterizes Patient 04's postoperative feelings of estrangement, as in other cases, can be understood by way of the deteriorative effects on the patient's self. We believe Patient 04 mostly experienced deteriorative consequences because Patient 04's feelings of estrangement largely appear to be correlated with a radical and ongoing sense of loss of control over her previous self, which reflects an involuntary and unintentional shift in her qualitative character. For instance, Patient 04 reported developing postoperative ongoing mania (medically diagnosed),

3. In our study all patients (4 out of 4; 100%) reporting that PD enhanced their life also reported a general feeling of postoperative self-continuity. Some patients clearly experienced the opposite (8 out of 13; 61%): namely, they self-reported how PD devastated their existence, and simultaneously reported how they experienced postoperatively various degrees, intermittences, and intensities of estrangement. For the five remaining patients (5 out of 13; 38%), their reports are too unclear to be classified. They experienced PD as intruding in their life, but didn't clearly report significant postoperative estrangement. Thus, they couldn't fit in our classification of restorative or deteriorative estrangement.

leading to a suicide attempt, as well as a substantial increase in impulsivity. Patient 04 said, "I cannot control the impulse to go off if I'm angry." As such, these findings appear to further corroborate the hypothesis that deteriorative self-experiences seem to qualitatively characterize the notion of powerlessness (Gilbert 2013a, 2015a), often manifested through involuntary self-harming actions/behaviors and/or loss of control.

It is a common mistake to think that postoperative feelings of self-estrangement are qualitatively deteriorative. Our study exposes that although DBS diminishes symptoms and restores patients' control over their lives, more patients experienced feelings of restorative estrangement rather than deteriorative estrangement. For instance:

> Patient 13: "[DBS] has allowed me to return almost to the person I was before . . . It's allowed me to be what I am, rather than change what I am," but while discussing this sudden restorative feeling, Patient 13 confessed that DBS adversely resulted in intermittent uncontrollable emotional sensitivity, to the extent of experiencing "a state of hysterics . . . I felt like I had lost my true self, it [is] way behind me."

Patient 13's experiences of restorative estrangement seem to separate an old self (practically understood), "DBS has partly restored my autonomy," and a postoperative qualitative character of this patient's selfhood, "I had lost my true self" as a result of the disease. Patient 13's comments illustrate that restorative estrangement can come in degrees. In this respect, a patient might experience self-rejuvenation while observing an involuntary shift in some aspects of her qualitative character. Similarly:

> Patient 11 first claimed: "it wasn't so much that it changed who you are, it rather restored who you are," but he later confessed that this novel restorative empowerment originated an uncontrollable phenomenon from which he dissociated his self and does not recognize himself: "There's nothing that I can do [to stop this] 'emotional incontinence'[4] as I call it. . . . If I had a choice I would say, 'Look see what you can do . . . to stop me from doing that.' Because it does get embarrassing."

Patient 11's postoperative feelings of restorative estrangement appear to increase some restorative capacities that the patient seems to identify with as essential for his preoperative and predisease self while admitting losing control of other aspects of his postoperative self. Aligning with these feelings of postoperative restorative estrangement:

> Patient 09 stated: "I felt I was 15 years younger after the operation . . . I felt so strong and confident . . . I could do anything . . . I felt so good I tried to move the pool table and I ruptured the disc in my back . . . I blame DBS for that because I felt so good, I did something that I couldn't have done when I was 21 and I don't know why I thought I could do it when I was 54 . . . I was in a wheel chair for 2 months."

Patient 09 "blames" the device for her ruptured disc (i.e., she accepts it was her fault, but she attributes her unreasonable confidence to the success of the device). We observed that sometimes the device provided such levels of heightened and uncharacteristic confidence that this resulted in other unforseen difficulties. For example, Patient 06 observed that he was bold in his activities, had difficulties in refraining from engaging in numerous commitments, and that he was in conflict with his wife: "I think I have been causing a bit of problems in my relationships by being just so full on. . . . I have to slow down that activity and make it more manageable for myself and my wife." In a similar way, Patient 09 was so confident in her newfound strength and physical capabilities that she was nearly permanently disabled when she attempted to lift and move a large pool table. In this way, DBS may be construed as so effective in relieving symptoms that it actually causes people to have a distorted view of their own capabilities. These distorted perceptions appear to induce the belief that patients have (some) enhanced capacities far in excess of their actual abilities. These distorted views of their capacities are often described in the language of sudden unexpected strength.

For instance, Patient 07 described her feelings after suddenly acting out of character during calibration. She reported starting walking and wanting to reach her husband's location (i.e., by foot), which would have taken her days. She explained her decision later by saying:

> "Oh God, I wasn't me, and I knew I wasn't me and there was nothing I could do about it . . . I knew what it was! I knew [DBS] had been turned up that day. Unlike the drugs which creep up on you, and you don't know what's happening. With [DBS] I knew what it was, so I knew it was fixable."

Here again, the device is similarly "blamed" for the sudden restorative strength. The device is responsible, "I knew what it was! I knew [DBS] had been turned up that day," for the distorted interpretation of her own capacities, "I knew I wasn't [my capacities]."

In parallel, while describing a sense of loss of control, Patient 04 also recognized DBS had given her increased feelings of strength (despite having mostly suffered from deteriorative estrangement):

> "I never had felt this lack of power or this giving of power—until I had deep brain stimulation . . . It's like the psychologist said [to me]: for a woman who had a very invasive brain surgery nine days ago and you've just walked 10 kilometres [to get to your appointment]. And on the way I stopped and bought a very uncharacteristic dress, backless—completely different to what I usually do."

Here, Patient 04's "lack of power" in some aspects of her character seems to be replaced by a "giving of power" with respect to other novel qualitative features of character—that

4. DBS has turned Patient 11 into a SNAG (patient words), a phenomenon beyond his control and putting him in discomfort. A SNAG is an acronym for "Sensitive New Age Guy."

is, a loss of control leading to a disinhibition that is characterized by some incommensurable feelings of strength.

The collected restorative narratives seem to indicate that DBS can distort patients' feelings of who they are or make them feel like they aren't themselves in some ways, capable of reaching unwanted limits beyond the preoperative self, for instance, as well as inducing unintended estrangement experiences of being in the world.

Given the preceding discussion, our study shows that the notion of self-estrangement seems to exist in association with certain common qualitative characters: namely, loss of control, which reflects a deteriorative estrangement, and distorted perception of capacities, which reveals a restorative estrangement.

EMBODIMENT: HAVING A BRAIN IMPLANT VERSUS BEING A BRAIN IMPLANT

Another way to understand how DBS might induce feelings of estrangement is to examine whether DBS has an effect in terms of being understood as a foreign intrusion; that is, whether the patients viewed the device as being a part of, or not a part of, themselves. For instance, for Patient 08, "It's just become part of me. It's more the other way around. It's more the DBS becomes a part of who you are rather than changing you." In this case the patient identifies with or sees him- or herself as continuous with his or her stimulated self. In contrast, when the device is seen as other or an outside force, it could contribute to feelings of self-estrangement.

However, our study found that the hypothesis—that if patients incorporate the DBS device into their self-image/body schema, then they will suffer less from self-estrangement—is not as robust as it sounds. In general, the patients interviewed did not notice the device in their body while it was doing its job in the background, despite having experienced some degrees and intermittent episodes of self-estrangement. Many noted that the device had a minimal presence in their body and that they did not typically notice that it was there. For example, Patient 13 declared, "I charged *myself* up this morning"; Patient 12 asserted, "I just don't know it's there. I don't feel invaded." Patient 06 affirmed, "It's part of me." Patient 05 indicated, "More a part of my body." Such responses appear to illustrate that patients use a language that seemingly incorporates the DBS device into their self or body image. Patient 13 clearly uses such metaphorical language; he does not say "I charged the devices up this morning" but rather "I charged myself up." Such language could indicate an embodied acceptance of the implant, of patients feeling like being one with the implant.

Nonetheless, we did find a correlative example between the device felt as an alien entity and a patient experiencing self-estrangement. Patient 04, who experienced the most severe and harmful effects of estrangement in our study, declared the following in response to the interviewer's question:

> Interviewer 1: "The implant, do you feel that it is part of you?"
>
> Patient 04: " No!"
>
> Interviewer 1: "You feel that it is alien?"
>
> Patient 04: "I hate it. I wish I could pull it out!"

Aside from this obvious case with Patient 04, who clearly experienced having a foreign device rather than it being part of her (i.e., language of being the device), most patients incorporated the devices. A few complained that it hampered, or had hampered, physical activity in the past. Patient 08 said, "I used to be able to feel the electricity going through my body but I don't feel it now … I forget about it most of the time, but I am aware because there is a hard little thing on your chest." Others had (perhaps unwarranted) fears about others interfering with the device accidentally (one research participant instructed hairdressers not to use clippers on her neck in case it damaged the wires). But in general, patients seemed to regard the device as something that had been integrated into their body. Most did not view it as a foreign entity that existed separately from their own self. The fact that patients tend to forget about the DBS implant might be construed as a positive thing because, in the end, they may focus less on their disease. This perception prevents DBS from having a felt intrusive quality. An interesting general point is that patients with non-rechargeable devices seemed not to notice the device as much, and it didn't have as much presence to them. Some patients with rechargeable devices noticed it a lot more, sometimes obsessing over its charge.[5]

In addition to exploring whether and how the implant altered patients' relationship to their body, we can explore the relationship to changed capacities of the body. Patients' measure of restoration often correlated with their physical abilities, and they declared being more independent (e.g., patients 16 and 17). However, as also noted in the preceding, some patients overestimated their capacities, in some cases beyond what they were capable of prior to the stimulation and the onset of PD. These experiences were often connected with a feeling of a loss or lack of control.

SUMMARIZING DBS POSTOPERATIVE SELF-ESTRANGEMENT

Our study demonstrates that there are various qualitatively different kinds of self-estrangement experiences. To speak of a postoperative estrangement implies that

5. There were some fears concerning what would happen if the device was not charged correctly (i.e., for those with rechargeable batteries). Some research participants took a very conservative attitude toward the battery charge and constantly monitored and topped up the battery. Others were very casual and let the battery run down a lot. The people who were concerned about monitoring the charge level were also people who seemed to have some anxieties about the implications of what would happen if the device ran out of power. Those who were more casual seemed to not harbor those sorts of fears. One person accidentally turned off his device at one point and only noticed a few hours later when he had trouble typing. But it was easily remedied and the event did not bother him or give him any further anxieties.

the relevant patient experience of deteriorative or restorative estrangement has an irreducibly subjective character specific to the implanted individual (Atkins 2000). The postoperative feelings of estrangement constitute a patient's first-personal point of view of a qualitatively deteriorative or restorative experience. Experiencing deteriorative or restorative self-estrangement does not mean a subject is experiencing X differently (e.g., X being an emotion, perception, thought, etc.), but rather that the experience of being the subject of X is qualitatively different. Experiencing X differently is not the same as experiencing oneself as qualitatively different. In other words, in some cases, the experience of X can feel different while the experiencer remains identical. Accordingly, an experiencer can feel estranged while the experience of X feels identical in some cases. In that respect, being self-estranged cannot be reduced to experiencing X differently; it rather involves an irreducibly novel experience of being the subjective character of X (experiencer is necessarily qualitatively different, but not necessarily X). Being a subject of X does not involve estrangement when the subjective experience is identical.

DBS ALONE DOES NOT DIRECTLY CAUSE POTENTIAL SELF-ESTRANGEMENT

There is a lack of consensus about how to adequately characterize the self vis-à-vis DBS treatment within the neuroethical literature. The current state of the debate is eclectic. Table 2 shows the numerous theoretical models of the self motivated to explain the effects of DBS on the self, including, but not limited to, the self as characterized by "self-representational capacities" (Synofizik and Schlaepfer 2008); as a "foundational-functional model" (Witt et al. 2013); as narrative self-constitution (Schechtman 2010) or relational narrative constitution (Baylis 2013); as an "enactive, affordance-based model" (De Haan et al. 2013); and as a "pattern theory of self" (Dings and de Bruin 2015). In addition to various models of the self, there is disagreement about the central concept affected by DBS, autonomy, and/or identity, and how to characterize these effects—for example, autonomy in terms of patient autonomy or competence, loss of control, and identity in terms of changes to personality or psychological continuity, to name a few. The conceptual understanding of agency also varies in these accounts. Most philosophical discussions concerned with potential DBS-induced effects on the self are not based on firsthand studies (see Table 2).[6] Also, when examining the firsthand studies from which the philosophical debate is inspired, we quickly observe that these studies describe a wide range of anatomical targets, as well as a diversity of unwanted personality changes associated with postoperative DBS intervention.

Further, there is a potential to claim that DBS directly causes these changes. It is often inferred in the nonscientific literature that DBS intervention poses a postoperative threat to personal identity, or induces some unwanted personality changes or has an unintended effect on the self. For instance, some have written, "The risk of becoming another person following surgery is alarming" (Witt et al. 2013) and "personality changes represent a threat to personal identity and agency" (Schechtman 2010). We categorize these positions as a "post hoc ergo propter hoc"-related assumption. Many neuroethical and philosophical documents[7] are guilty of perpetuating this assumption with little examination or scrutiny.

What do subjective self-reports from PD patients with DBS show us about the potential for self-estrangement? Our study found that 8 patients among 17 (47%) experienced some degrees of, and intermittent episodes, of self-estrangement. These results align with clinical reports, which indicate that the phenomenon of "becoming a different person" after DBS intervention may not be solely attributed to the electrical stimulation itself but could be caused by treatment adjustments post surgery or by disease progression (Volkmann, Daniels, and Witt 2010). As such, the prevalence and incidence of self-estrangement might not be exclusively correlated with a specific DBS target and/or stimulation parameter but rather should be seen as a result of the interaction between the neural and glial effects of electrode insertion during surgery (Vedam-Mai et al. 2012) and electrical stimulation, adjustments in medication, and natural progression of the disease (Volkmann, Daniels, and Witt 2010), especially when DBS is used in patients with neurodegenerative disorders where changes to personality and identity are inevitable regardless of treatment course and choices. Although DBS affects spiking activity and neurotransmitter release in local (Hammond et al. 2008; Cheney et al. 2013) and distant circuits (Li et al. 2014), turning off stimulation won't conclusively allow dissociation of personal identity changes as a result of electrical stimulation from DBS and as a result of associated treatment modifications and disease prognosis. This is further complicated by the potential of DBS to induce long-term synaptic changes in the brain (Herrington, Cheng, and Eskandar 2015). However, some case reports do seem to suggest that turning off the stimulation ends, for instance, an episode of mania or impulsivity (Tsai et al. 2010), and if longer term synaptic changes are made, then we might not expect the personality changes to disappear with the removal of stimulation (Gilbert 2013b). Overall, changes in identity, personality, and self-awareness during DBS not only should be attributed to the DBS target structure, surgical trajectory, and stimulation

6. We do not have enough space to adequately characterize the accounts in Table 2 concerning the potential DBS-induced effects on the self. Rather, we aim to examine a patient's postoperative phenomenological experience of first-personal or subjective change, especially responses, or feelings of, self-estrangement.

7. Though not necessarily all those listed in Table 2.

Table 2. Survey of the existing model of DBS-induced effect on the self.

Central concept of ethical significance given impact of DBS	Discussed by	DBS impacts characterized by	Quote	Model of self
Autonomy and related concepts	Synofzik and Schlaepfer (2008)	The "level" and "extent" of changes to naturalistic notion of personality	"The ethically decisive question is not whether DBS alters personality or not, but whether it does so in 'a good or bad way' from the patient's very own perspective." (1514)	Naturalistic model of self as the "objective, biological-cognitive representational system with special characteristic self-representational capacities" (1513)
Autonomy and related concepts	Schermer (2011)	Perceived changes to narrative identity	"[W]hether or not the patient himself perceives the changes in his personality, mood, behavior, or cognition brought about by DBS as disruptive of his personal narrative identity." (2)	Narrative identity
Autonomy and related concepts	Gilbert (2013a, 2015, 2017)	Loss of control and powerlessness	"Postoperative self-estrangement may enhance or restore one's control over one's life or illness. However, in some cases, DBS radical modifications of the self may lead to a loss of control or experiencing feelings of powerlessness." (109)	#
Autonomy and related concepts	Mackenzie and Walker (2015)	Autonomy competence	"This distress, in our view, points to threats to autonomy rather than to identity or authenticity, as the salient concern underlying narratives of self-alienation." (390)	Relational, narrative understanding of identity and autonomy
Authenticity and related concepts	Johansson et al. (2011)	Personality changes and impacts on authenticity	"The concept of authenticity . . . provides a means to entangle both philosophically and generally held intuitions regarding normative claims connected to personality changes." (2)	Normative thesis of authenticity

Authenticity and related concepts	Kraemer (2013)	Felt-authenticity and felt-alienation	"For some, alienation can be brought about by neurointerventions because patients no longer feel like themselves. But, on the other hand, it seems alienation can also be cured by DBS as other patients experience their state of mind as authentic under treatment and retrospectively regard their former lives without stimulation as alienated." (483)	Identification/endorsement with felt-authenticity and felt-alienation
Identity and related concepts	Gisquet (2008)	Changes in personality and loss of control over managing one's life and illness	"Cerebral implants are a unique form of biographical disruption . . . [T]he patient loses control over managing the illness and experiences significant changes in personality." (1850)	Biographical
Identity and related concepts	Focquaert and De Ridder (2009)	Changes in personality and self-perception	"Neuromodulation via implanted electrodes can influence narrative identity directly and indirectly." (2)	Narrative identity
Identity and related concepts	Glannon (2009)	Changes in thought and personality	"Stimulating the brain . . . may alter a range of mental states critical to thought, personality and behavior. This can disrupt the integrity and continuity of the psychological properties that constitute the self and one's experience of persisting through time as the same person" (289)	Narrative identity
Identity and related concepts	Klaming and Haselager (2010)	Disruptions of psychological continuity impact on patient competence and responsibility	"DBS may . . . influence mental states critical to personality to such an extent that it affects an individual's personal identity . . .. [This] raises a number of ethical and legal questions. . . . [I]nduced changes . . . [may] result in damage caused by undesirable or even deviant behavior. Disruptions in psychological continuity can in some cases also have an effect on an individual's mental competence." (527)	Psychological criteria of personal identity

(*Continued on next page*)

Table 2. Survey of the existing model of DBS-induced effect on the self. *(Continued)*

Central concept of ethical significance given impact of DBS	Discussed by	DBS impacts characterized by	Quote	Model of self
Identity and related concepts	Witt et al. (2013)	Patient's core attitudes	"Ethical evaluation of deep brain stimulation as treatment for Parkinson's Disease is complicated by results that can be described as involving changes in the patient's identity. The risk of becoming another person following surgery is alarming for patients, caregivers and clinicians alike." (499)	Foundational-function model: self as a set of core attitudes
Identity and related concepts	Mecacci and Haselager (2014)	Psychological maladaptations and conceptual schemes concerning the relationship between mind and brain	"We hypothesize that the frequently reported maladaptations might be partially caused by a conceptual emphasis on 'braincentric' materialism." (31)	Embodied embedded stance toward the mind–brain relationship
Identity and agency	Schechtman (2010)	Narrative identity and agency/disruption of the narrative flow	"Stimulation-related psychological and personality changes represent a threat to personal identity and agency." (133); "DBS can pose a threat to identity by threatening narrative." (139)	Narrative self-constitution
Identity and agency	Baylis (2013)	Disruption of the balance between how a person sees and understands herself and how others see and understand her	"From the perspective of relational personal identity, when DBS dramatically disrupts the narrative flow, this disruption is best examined through the lens of agency." (514)	Relational narrative identity
Identity and agency	Lipsman and Glannon (2013)	Personal identity and a sense of free agency	"Brain implants . . . have significant implications for what it means to persist as the same person and be the source of one's thoughts and actions." (465)	Neurobiology of identity (narrative and numerical) and identification (Frankfurt)

Identity and agency	Dings and de Bruin (2016)	Aspects of the self—embodied, experiential, affective, intersubjective, psychological/cognitive, narrative, extended, and situated	"Our aim in this paper is to develop a pattern theory of the self, and to explain how this theory can be applied at the level of pattern types and pattern tokens." (fn 8, 158)	Pattern theory of self
Identity and agency	De Haan et al. (2013; 2015)	Patients experience a richer field of affordances and act more flexibly on these new affordances	"It turns out that patients may experience profound changes as the result of DBS treatment. It is not just the symptoms that change; patients rather seem to experience a different way of being in the world." (2013, 1)	Enactive, affordance-based model

parameter, but also should account for patient history, disease attributes, and other forms of treatment adaptations such as medication adjustments and psychotherapy.

At this point in time, it is relatively difficult to isolate the cause of these postoperative changes, though they have been associated with DBS. To the best of our knowledge, no neurobiological studies claim that postoperative personality changes can be predicted solely on the basis of DBS itself or an exclusive neurobiological cause. Even in a tragic case where a patient implanted with DBS died by suicide, an indirect causal explanation was used in the legal case to argue that postoperative changes are "more likely than not to have been due in significant but unquantifiable measure to the DBS" (Dillon 2014).

A similar relationship is seen in Parkinson's disease patients who develop compulsive behaviors or impulse control disorders (ICD) (e.g., compulsive gambling, shopping, and eating) associated with dopamine replacement therapy. As seen during our interviews, many patients reported self-changes due to medication. This correlates with other findings that show that almost 17% of individuals with PD who are treated with dopamine agonists (DA) will develop an ICD (Ambermoon et al. 2011). There is strong evidence that DA plays an important causal role: These behaviors tend to emerge soon after commencing the medication or increasing doses, and they often resolve when the medication is stopped, as some of our patients reported. There is also a plausible explanation for how dopaminergic medications would lead to compulsive behaviors. The medication only plays a partial causal role: the overwhelming majority of individuals do not develop these disorders. There are also predictable individual differences that identify the likelihood of developing a compulsive behavior, such as having a personal or family history of addictive or impulsive behavior. The sorts of behaviors that emerge appear to be heavily influenced by social factors: Women tend to engage in compulsive shopping and eating, while men are more likely to develop pathological gambling or hypersexuality.

In short, this work does not advocate that DBS alone directly causes potential personality changes.

LIMITATIONS OF THE STUDY

There are a number of limitations in this study. It is important to clarify what the study was, and was not, doing. There is concern with the lack of data concerning first-personal phenomenological reports or assessments of neural implants, which this article in some sense seeks to address. Connected to this point is the concern that no generalizable conclusions can be drawn from such limited data. While looking at the phenomenology of DBS might be a useful tool for describing the lived experiences of implanted patients, it remains severely impoverished as a theory for explaining it (Sholl 2015). However, we are not attempting to draw generalizable conclusions on the basis of numbers, but rather, we aim to examine phenomenological first-personal reports to inform understandings of the impacts of DBS on patients' self, with a focus on self-estrangement.

First, it should be recognized that drawing on subjective or first-personal phenomenological accounts of how a person feels about or experiences their implant does not provide us with enough context to assess the (objective) accuracy of these accounts. Estrangement is not necessarily self-perceived. As other studies have demonstrated, relatives are often more sensitive to alterations in self than the patients themselves (Pham et al. 2015). In addition to what we discussed in the previous section, Patient 03 reported, "I don't feel different at all. Some people said to me that I am a bit different." Correspondingly, Patient 06 reported, "I think I have been causing a bit of problems in my relationships." Also, the epistemic role of the first-personal perspective may be limited, particularly in the case of induced mania. We are not questioning the what-it's-likeness but rather the consistency of the narration. As family members pointed out to Patient 04, "They said they don't recognize me . . . I am so impulsive and seem to change my mind all the time." Here it is not the experiential-qualitative character of being manic which is problematic, but rather the consistency of the narrative account. Families and social context are an essential measurement of how patients are experiencing potential estrangement, even if patients do not perceive it. An extended study would not only involve interviewing the implanted patients, but also their close relatives. In the current study, patients were asked whether their relatives mentioned any postoperative changes, but systematically interviewing patients' relatives would have likely generated more data.

Second, and more importantly, our study merely asked patients to report on their perception of self-change. As such, it provides a limited amount of information about patients' uptake and adaptation over time. As such, there is insufficient evidence to draw conclusions about how the implants affect autonomy and identity and consequently to draw conclusions about the impacts on autonomy and identity. An extended version of the study should also include interviews made before the intervention, and at least two follow-ups; this would add important insights regarding the degree of "self-deception" of patients when remembering their state prior to surgery. Further, the study should include focus on the patient's engagement with the world and his or her implant, in addition to reporting on perception of self-change.

Despite these identified limitations, we strongly believe that we can draw some robust and common findings from the patient postoperative narratives, as we have done in the preceding, and on the basis of these findings make some conclusions, as summarized in the following. Further, exploring patient's first-personal experience of DBS can inform and guide patients through decision-making processes leading to implantation, and can also answer questions of patients currently experiencing self-estrangement phenomenon.

CONCLUSIONS

Subjective self-reports from PD patients with DBS help us to understand some aspects of potential postoperative self-estrangement. The way patients perceive themselves through pathology will likely dictate the way they will experience potential DBS-induced self-estrangement; self-perception through pathology will likely dictate degrees of whether patients self-perceive DBS as something that is restorative. The notion of self-estrangement seems to exist in association with certain common qualitative characters: (1) loss of control and (2) distorted perception of capacities. The first is mostly associated with a deteriorative sense of the self, and the second is largely related to a restorative one. Most implanted patients we interviewed experienced a shift in their self-perception, mostly in a restorative sense, especially during calibration. Some feelings of deterioration were experienced in relation to powerlessness, which resulted in severe harm in one case. This evidence supports the hypothesis that postoperative feelings of powerlessness play a crucial role in causing harm (Gilbert 2013a, 2015a). This study demonstrates that DBS, as a whole, increases autonomous restorative power over one's self, rather than a deterioration of the self. This is anecdotally supported by our interviews with patients who reported a sensation of empowerment. The explanation for this may reside in the concept of embodiment, where the device is felt to become part of the individual, rather than as a foreign despot exerting control (Amadio and Boulis 2015).

It appears from these clusters that most patients experience a proportionally restorative sense of the self. This evidence justifies the claim that, generally speaking, DBS is not a threat to personal, but some patients might not experience well any form of estrangement. Patients would benefit from being informed ahead of any potential risks, prior to consenting to being implanted, as in other types of invasive brain intervention (Viaña, Vickers et al. 2017; Gilbert et al. 2014; Viaña, Bittlinger et al. 2017; Gilbert 2015b; Bretzner et al. 2011; Gilbert, Vranic, and Hurst 2013; Gilbert 2014; Gilbert et al. 2015; Vranic & Gilbert 2014; Gilbert & Cook 2015; Gilbert 2017; Gilbert & Dodds 2013; Gilbert & Focquaert 2015; Gilbert & Vranic 2015).

This study highlights the importance of the first-personal perspective and subjective assessments when considering the impacts of implants and the need for more assessments. More significantly, however, we argue that further and more fuller phenomenological exploration of how patients respond to their neural implants is needed in order to draw conclusions about the impacts of DBS on autonomy and identity. This would involve interrogating patients' agency over time so that we can make an assessment of whether initial disruptions, feelings of self-estrangement, and failures in decision making are short-term or long-term phenomena. Furthermore, this would involve assessing how patients live with their implants, with a focus on whether the implant facilitates or hinders their capacities to engage in the world.

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APPENDIX: SEMISTRUCTURED INTERVIEW SCRIPT

These are examples of generic questions. They are an indication of the structure to be followed during the interviews, rather than the actual questions to be asked to patients. The choice of words, terminology, or languages may change slightly for each patient.

1. Potential questions regarding postoperative sense of the self.
   i. What was it like to live without the deep brain stimulation (DBS) device? Did you feel comfortable in yourself with your medical condition? How did you feel that your medical condition affected your life?
   ii. What is it like to be implanted with DBS? Do you feel any significant difference from before the device compared to after it was implanted?
      - Please provide some examples. Did you expect to find differences or changes prior to the operation?
   iii. Have others commented on any changes to you (e.g., personality, habits, etc.) since being implanted? If so, do you agree with them? Why or why not?
   iv. (Depending on previous answers) Do you think you may change/change more in the future as a result of this intervention?
2. Potential questions regarding the sense of control.
   i. Prior to the implantation of DBS, how would you describe your control over your life? (e.g., through habits, daily activities, etc.)
   ii. Do you feel the device has increased your autonomy (e.g., making you less dependent on others)? For instance, has it improved your life, control on symptoms? Has it given you back more control over your life?
   iii. Have others commented that you have better control over your life/symptoms/yourself? Do you agree with them? If not, why not?
   iv. (Depending on previous answers) If you experienced the device as form of control, does it feel authentic? From your own personal experience, do you see it as a novel control?