

Some ethics of deep brain stimulation



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Introduction

In an oft-cited case report, [Schüpbach et al. \(2006\)](#) describe Patient 1, a 38-year-old female journalist, married with one child, who had Parkinson's disease (PD) with severe dyskinesias. Six months after undergoing deep brain stimulation (DBS), her motor symptoms significantly improved. But after 18 months of stimulation: “she was no longer able to work, had a loss of inspiration and a taste for her work and for life in general,” and she said, “Now I feel like a machine, I've lost my passion. I don't recognize myself anymore.” ([Schüpbach et al., 2006](#), p. 1812).

In contrast, patients in [Klein et al.'s \(2016\)](#) qualitative study, who underwent DBS for obsessive-compulsive disorder (OCD) or treatment resistant depression (TRD) report that after stimulation: “I'm me without depression” (Patient F3) or “back to sort of a baseline ... back to yourself” (Patient F2) ([Klein et al., 2016](#), p. 144).

These studies (and many others like them) have sparked a vast literature about the ethical issues raised by DBS. The examples cited here raise a number of questions: How should we think about the changes that patients report post-DBS? Does DBS ever really turn patients into new people or return them to their old selves? What ethical issues are likely to arise as DBS technology progresses?

This chapter addresses these questions in three sections. In section “Clinical uses of DBS,” we review the recent clinical literature on DBS. In section “DBS and threats to identity,” we consider whether DBS poses a threat to personal identity. In section “Surveys of judgments of identity change” we argue for engagement with recent psychological work examining judgments of when identity changes.

Clinical uses of DBS

In this section, we review recent research on deep brain stimulation (DBS) for Parkinson's disease (PD) and then psychiatric conditions, including obsessive-compulsive disorder (OCD) and treatment resistant depression (TRD). We conclude with a brief discussion of next-generation DBS technologies.

DBS and PD

In general, DBS involves a surgically implanted battery-operated device which delivers electrical stimulation to a specific brain region. An electrode is inserted through

a small opening in the skull and situated within a specific brain region. A pulse generator, which is about the size of a stopwatch, is implanted near the collarbone. An insulated wire connecting the electrode and the pulse generator is then passed under the skin of the head, neck, and shoulder ([National Institute of Neurological Disease and Stroke, 2017](#)).

The first commercially marketed DBS devices were introduced by Medtronic in the 1970's to treat chronic pain. [Benabid, Pollak, Louveau, Henry, and De Rougemont's \(1987\)](#) paper later demonstrated the efficacy of thalamic stimulation for tremors associated with PD. In the United States, DBS was approved for treatment of PD in 2002. As of 2012, over 40,000 patients had been treated with DBS ([Gardner, 2013](#)). Today, PD, dystonia, and tremor are the three main indications for DBS therapy ([Munhoz et al., 2016](#)).

Areas in the basal ganglia and thalamus are the main targets, with the subthalamic nucleus (STN) and globus pallidus internus (GPI) being the most common ([Liu et al., 2014](#)). Other targets include the ventral intermediate nucleus of thalamus, ventral oral anterior/posterior nucleus of thalamus, and zona incerta ([Hariz, Blomstedt, & Zrinzo, 2013](#)).

In most cases, DBS therapy is used for PD patients whose symptoms can no longer be adequately controlled with medication. There is some debate, however, about whether DBS ought to be used earlier in the disease course, with some evidence suggesting that the severity of later-term symptoms can be reduced, and disease progression slowed ([Hacker et al., 2015](#); [Schüpbach et al., 2013](#)). At any rate, patients undergoing DBS are, on average, around 60 years old, with a mean disease duration of 12 years. This targeted population accounts for less than 2% of all PD patients ([Hickey & Stacy, 2016](#)).

Since the early 2000's a number of large-scale, randomized, controlled clinical trials have demonstrated the efficacy of DBS for PD and various movement disorders (e.g., [Macerollo & Deuschl, 2018](#); [Okun et al., 2009](#)). These studies consistently find that patients receiving DBS (compared to patients receiving only medication) have significantly better quality of life outcomes, reduced duration and severity of motor symptoms, and increased mobility. A recent review of the effects of DBS of non-motor symptoms for PD patients concludes, "overall, cognitive function generally remains stable," but "after surgery, decreased verbal fluency is consistently reported and apathy possibly worsens" ([Kurtis, Rajah, Delgado, & Dafsari, 2017](#), p. 9).

Apathy has an estimated prevalence of between 15% and 70% among PD patients, depending on disease severity and the diagnostics used. [Pagonabarraga, Kulisevsky, Strafella, and Krack \(2015\)](#) classify apathy into four subtypes: (1) reward deficiency syndrome, (2) emotional distress, (3) executive dysfunction, and (4) autoactivation deficit. According to their review, most studies do not find significant increases in apathy post-DBS (compared to non-surgical PD treatment), so long as recommended post-operation medication regimens are followed. Still, while some patients report an improvement in apathy symptoms after STN-DBS, others report worsening symptoms.

DBS and OCD

Other clinical applications for DBS include neuropsychiatric conditions such as obsessive-compulsive disorder (OCD). People with OCD suffer from either obsessions

(unwanted, intrusive thoughts), compulsions (repetitive actions to reduce anxiety), or both. Among patients with treatment-refractory OCD, DBS has been explored as a last-resort alternative to ablative neurosurgery. DBS targeting the ventral capsule and ventral striatum for OCD represented the first FDA approval (under a humanitarian device exemption) for a psychiatric disorder (Nuttin, Cosyns, Demeulemeester, Gybels, & Meyerson, 1999).

Kisely et al. (2014) conducted a review and meta-analysis of research using DBS for intractable OCD. In five studies, symptoms reduced in patients who received active (as opposed to sham) treatment. However, one third of patients reported serious adverse effects relating to the surgical operation or the stimulation. A larger but less restrictive meta-analysis by Alonso et al. (2015) found that the percentages of subjects with a clinically significant reduction in symptom severity varied widely from 10% to 61.5%. These mixed results underscore that the targets of DBS for OCD are not yet well understood (compared to DBS for PD). While DBS does appear to reduce symptoms for treatment-refractory OCD, these results must “be tempered by the fact that, in terms of clinical significance, this represents partial, rather than full, remission” and “the procedure was associated with significant adverse effects” (Kisely et al., 2014, p. 3539).

DBS and TRD

Treatment resistant depression (TRD) has been the other main psychiatric indication for DBS therapy. The prevalence of major depression is estimated at 14.6% in high-income countries (Kessler & Bromet, 2013). “Treatment resistant depression” usually refers to the estimated 30% of patients who do not respond to multiple stages of anti-depressant medications or electroconvulsive therapy.

Malone et al. (2009) conducted the first open-label trial of DBS for TRD. In the first randomized clinical trial, Dougherty et al. (2015) targeted the ventral capsule/ventral striatum and failed to observe a significant difference between the active and sham DBS conditions during the blinded phase. Bergfeld et al. (2016) targeted the ventral anterior limb of the internal capsule (vALIC) for TRD and classified 10 of 16 patients as “responders” to vALIC-DBS because their depressive symptoms significantly improved: “responder” scores were significantly lower on the 52-point Hamilton Depression Rating Scale during active DBS ($M = 13.6$) compared to sham DBS ($M = 23.1$). Most of the reported adverse side effects due to stimulation were transient (e.g., headache, agitation, disinhibition, etc.) and tolerated by patients, or resolved by lowering the voltage. More recently, Holtzheimer et al. (2017) failed to observe a significant difference between active and sham DBS for TRD.^a This variation in efficacy could be due to a number of factors, including difficulty in finding the precise place to implant electrodes, and differences in stimulation optimization strategies.

^a For a recent overview, see also Bari et al. (2018). Thanks to Dan Stein for calling these sources to our attention.

The future of DBS

The big picture remains fuzzy. [Hariz et al. \(2013\)](#) report that over 40 brain regions have now been identified as DBS targets for more than 30 different clinical disorders, but despite more than a quarter of century of modern DBS, spanning dozens of clinical applications in which dozens of different brain areas have been targeted, the clinical use of DBS is evidence based in only three conditions (PD, dystonia, and tremor) and only in three targets (the STN, the GPi, and the Vim). Furthermore, even in its most common application over the last 25 years (i.e., PD), with tens of thousands of operated patients, several issues are still not settled: What is the best target for DBS in PD? What is the mechanism of action of DBS? What is the effect of DBS on nonmotor symptoms, axial symptoms, and impulsivity? Which is the best target for the tremor: Vim, caudal zona incerta, or STN? When should we offer DBS in the course of PD? ([Hariz et al., 2013](#), p. 1789).

As the academic cliché goes (higher quality and higher powered) future research is needed.

Efficacy might be improved by new versions of DBS. The interventions described in this section have all been “open-loop” in the sense that the DBS device provides a more or less constant level of electrical stimulation. Newer “closed-loop” DBS uses a single device to both monitor brain signals and deliver variable electrical current. Electrical markers of neuropsychiatric symptoms could be used to tailor the delivery of stimulation, presumably more accurately and efficiently. Patients might even be able to control the level of stimulation without help from a doctor. Such devices raise potential ethical challenges that we will consider in following sections (for a review, see [Goering, Klein, Dougherty, & Widge, 2017](#)).

DBS and threats to identity

In a pioneering article on neuroethics, [Roskies \(2002, p. 500\)](#) noted that “in investigating the brain, we investigate the self,” and she raised questions such as “is personal identity a brain-based notion?” and “will certain medical or technological therapies change *who we are*?” Others have asked similar questions about drugs, such as Prozac ([Kramer, 1993](#)), but DBS raises Roskies’s questions specifically about surgical brain interventions. In this section, we review ethical theorizing about DBS with a special focus on its implications for self and identity.

One of the most-cited discussions about the ethical implications of DBS is [Schüpbach et al. \(2006\)](#). Consistent with results reported above, the researchers found that in a population of 29 patients undergoing STN-DBS for PD, most reported improvements in motor symptoms, activities of daily living, and quality of life. However, Schüpbach et al. also found that various forms of social adjustment did not improve, and some significantly worsened. For example, marital conflicts were reported in 17 of the 24 married couples. Over half were unable to return to professional activities after surgery. Two-thirds expressed feelings of strangeness and unfamiliarity with themselves, saying things like “I don’t feel like myself anymore,” and “I haven’t found myself again after the operation” (p. 1813).

Similarly, the case report quoted at the start describes a patient whose motor handicap improved 75% but who “was no longer able to work, had a loss of inspiration and a taste for her work and for life in general” and said, “I don’t recognize myself anymore” (Schüpbach et al., 2006, p. 1812). This passage and others like it probably explain why Synofzik and Schlaepfer (2008, p. 2) argue that the question about whether DBS alters the self “seems to be one of the fundamental ethical questions.”

Neuroethicists have extensively considered how DBS might affect identity (Focquaert & DeRidder, 2009; Glannon, 2009; Schechtman, 2010; Schermer, 2009); agency (Baylis, 2013; Lipsman & Glannon, 2013) autonomy (Goddard, 2017), and authenticity (Kraemer, 2013a, 2013b). Many of these accounts are nuanced and combine these different themes, but they agree that the kinds of changes brought about by DBS (e.g., apathy, estrangement) must be carefully weighed against the benefits (e.g., improved mobility, reduced tremor).

A recurrent worry is that the kinds of changes brought about by DBS are philosophically quite profound (e.g., no longer feeling like a genuine author of one’s desires and actions) but not captured by existing clinical assessment tools. In this section, we will consider one illustration of this worry and then a reply.

Witt, Kuhn, Timmermann, Zurowski, and Woopen (2013, p. 501) echo the common refrain that “DBS may change the patient’s identity.” They dub this the “change-of-identity thesis” (CIT) and correctly note that “the CIT figures prominently in the current debate on the ethical implications of DBS.” Of course, in order to evaluate CIT, we first need to get clear on what is meant by “identity.” No small challenge. To do this, Witt and colleagues begin by marking Schechtman’s (2007) distinction between questions of *re-identification* and questions of *characterization* in the personal identity literature in philosophy.

Reidentification questions concern quantitative identity: What makes X at T_1 the same as Y at T_2 , such that $X=Y$? This issue is not what is in question in cases of DBS. Nobody doubts that the person after the operation is quantitatively identical with the person before the operation. This patient still owns the same home, has the same bills to pay, and is married to same person as before the operation. It is widely accepted that if DBS threatens identity, it does not do so in this quantitative sense.

Instead, DBS potentially threatens identity in the sense of characterization. Characterization questions roughly concern qualitative identity: What makes X who they are? What gives them their distinctive personality?

Not all characteristics matter, so another distinction is needed. Within characterization, the authors further distinguish between *core* and *periphery* attitudes. One attitude is closer to the core than another attitude if and only if the first is “more important for and more distinctive of the person” (p. 503). For example, attitudes about soft drinks are usually more peripheral than attitudes about religion. A patient does not become a new person if all that changes are peripheral attitudes. A person changes in the relevant sense, on their view, only when their core attitudes change.

But which attitudes are core? After rejecting competitors, Witt and colleagues settle on a *foundational function* account. Much as a house’s foundation supports its walls, some of our core attitudes support other attitudes. Roughly, if a person’s foundational

core attitudes change enough, then they change as a person. Below, we will consider how morality might play this role of a foundational core attitude.

On this view, the ethical permissibility of DBS hinges on the extent to which DBS threatens these foundational core attitudes and also on how these threats trade off against potential benefits. Thus, to determine when DBS is morally permissible, we need some way to measure foundational core attitudes. For this purpose, Witt et al. advocate “longitudinal studies combining a philosophical investigation of the concept of “personal identity,” semi-structured interviews of patients and their caregivers, and validated quantitative test instruments.” (p. 509). Of course, this proposal is underspecified. For one, it does not address the tradeoffs mentioned above. Moreover, it is hard to design and execute longitudinal studies and well-validated psychometrics, especially for hard to reach clinical populations like DBS candidates. Still, we agree that a growing body of empirical research can help to make progress on these issues.^b

Before introducing this empirical literature, we should consider an opposing view on the change-of-identity thesis (CIT). Baylis (2013), for example, criticizes CIT on three grounds: CIT is *false* because it misconstrues identity as static and essentialist instead of relational and narrative. CIT is *misdirected*, because the real threat to identity (understood relationally) is discriminatory attitudes toward individuals with motor and other disabilities. CIT is also *trivial*, insofar as any experience integrated into a personal narrative could be potentially threatening. None of this denies that DBS raises ethical issues. Instead, Baylis thinks that the issues should be framed in terms of threats not to identity but instead to *agency*—that is, being able to “meaningfully contribute to the authoring of her own life...to the cyclical and iterative process of projecting, defending and revising a self-narrative” (p. 525).

It is beyond the scope of this chapter to adjudicate between the “essentialist” and “relational” accounts of identity invoked here. Still, the fact that these views of identity may be irreconcilable motivates another argument against CIT.

A general skepticism about neuroethicists’ ability to converge on an operative definition of identity (among other issues) leads Müller, Bittlinger, and Walter (2017) to argue that the philosophical debates about identity change are what actually pose a threat to DBS patients. On their telling, CIT often relies on cherry-picked interpretations of DBS case reports that are used to support controversial metaphysical accounts of personal identity. This characterization of the literature is controversial (Nyholm, 2017), but their central claim is that metaphysical interpretations of CIT are “inappropriate for ethical analysis of personality changes after brain interventions” and also for revisions of law and medical practice.

For example, if ethicists, lawyers, and clinicians truly regarded patients who presented personality changes after DBS as new persons, as CIT seems to suggest, then advance directives of the (pre-DBS) patient must be disregarded. Because advance directives are “effective legal instruments that allow patients to exercise their autonomy,” a controversial metaphysical account of identity which would deprive patients

^b For further discussion of some of these difficulties, see De Haan, Rietveld, Stokhof, and Denys (2017), esp. pp. 22 ff.

of this right “would harm them and restrict their liberty. In this sense the personal identity debate is a threat to patients” (p. 2).

We raise these questions about CIT not to resolve them once and for all, but rather, to highlight that these complex issues will not be solved without meaningful collaboration between philosophers, scientists, and clinicians. Witt and colleagues call for more nuanced psychometrics. Despite their criticisms of Witt et al., Müller et al. (2017) nonetheless agree that, “existing personality tests are insufficient to investigate all aspects of personality changes, feelings of self-estrangement and psychosocial adaptation problems, and new standardized psychometric instruments need to be developed” (pp. 10–11). Baylis calls for more nuanced philosophical analysis. We call for both better scientific assessments and more rigorous philosophical analysis, as well as increased collaborations between these camps.

In the following sections, we will illustrate how psychologists and philosophers can work together to make some progress on disputes about CIT and the ethics of DBS.

Surveys of judgments of identity change

When does one person become another person? This question appears, on the surface, to be descriptive rather than evaluative. We would seem to be able to identify the same person without knowing which person is good or bad. That assumption has come under fire recently in ways that will clarify the debate over CIT and illuminate ethical issues surrounding DBS.^c

The essential moral self

In a series of studies, Strohminger and colleagues explored lay intuitions about identity change. Surprisingly, aside from a few off-handed citations (e.g., Nyholm, 2017; Nyholm & O’Neill, 2016; Pugh, Maslen, & Savulescu, 2017), this research has not received the attention it deserves in the neuroethics literature.

In an early study, Strohminger and Nichols (2014) conducted a number of experiments where participants read vignettes about a character undergoing different kinds of changes. For example, in one experiment, a character named Jim underwent a “partial brain transplant” following a car accident. Participants were asked to imagine that it is the near future, and neuroscience has advanced to the point that brain tissue can be grown in a lab and then transplanted into patients. The key outcome measures were questions about Jim like “to what extent are they the same as before?” or “do you agree that they are the same person as before?”

There were five between-subjects conditions in the experiment: a “control” condition in which Jim’s personality and behavior are described as being exactly the same after the transplant; an “agnosia” condition in which Jim is exactly the same as before, except he lacks the ability to recognize objects; an “apathy” condition in which he is exactly the same as before, except that he has lost his desires; an “amnesia” condition

^c Parts of this section draw from and expand upon Earp, Skorburg, Everett, and Savulescu (2019).

where he is exactly the same as before, but he no longer has pre-transplant memories; finally, a “morality” condition in which Jim loses his moral conscience but is otherwise exactly the same as before. Participants rated the extent to which they agreed with the statement: “The transplant recipient is still Jim.”

Surprisingly, Strohminger and Nichols found that when Jim lost his moral conscience, he was judged to be more of a different person than in any other condition. One reason this result might seem surprising is that moral conscience plays little role in philosophical discussions of personal identity. Instead, many philosophers claim that *memories* determine personal identity, so they might have predicted that the amnesia condition would produce judgements of greater identity change. Future work in philosophy should explore the extent to which morality and memories are related to the core, foundational attitudes discussed above.

Although less than morality, the apathy and amnesia conditions (there was no significant difference between them) did produce the second-largest judgements of identity change. The effect of apathy could help to make sense of the journalist case in [Schüpbach et al. \(2006\)](#). When people lose their desires and become apathetic, these results suggest that they are perceived as more of a different person than when they lose other cognitive abilities (such as the ability to recognize everyday objects). Moreover, in a free response follow-up question, 23% of participants spontaneously volunteered that the desires in the apathy condition give a person their identity (while 61% of participants said this about morality). We will have more to say below about the connections among apathy, morality, identity, and DBS.

In another experiment, [Strohminger and Nichols \(2014\)](#) asked participants to imagine that they were meeting an old friend whom they had not seen in years and then to indicate the extent to which a variety of changes would impact their friend’s identity. Importantly, Strohminger and Nichols included not only basic cognitive traits (e.g., attention span, planning, etc.) and moral traits (e.g., generous, cruel, etc.), but also personality traits (shy, artistic, etc.). This is worth flagging in the present context because neuroethicists in the CIT debate (e.g., [Northoff, 2004](#)) often distinguish between *personality* and *identity*, claiming that changes to the former brought about by DBS do not entail changes to the latter. In any case, consistent with previous results, Strohminger and Nichols find that changes to moral traits scored higher in terms of impact on identity than every other kind of trait, including major changes to cognition and personality.

Some of the vignettes in these studies are admittedly far-fetched (involving, e.g., magic pills, time-travel, and reincarnation). Nonetheless, as [Strohminger and Nichols \(2014\)](#) point out, these results seem relevant for non-sci-fi cases: “disruptions of identity due to medical syndromes and their treatments are likely pervasive; our work suggests that they will be particularly dramatic for outcomes that affect moral faculties” (p. 169). DBS provides a crucial case.

The result that moral traits are perceived as essential to personal identity has now been replicated many times. [Strohminger and Nichols \(2014\)](#) find this effect in real-life cases of patients with frontotemporal dementia. [Heiphetz, Strohminger, Gelman, and Young \(2018\)](#) find that like adults, 8- to 10-year-olds also judge that people change more when their moral beliefs change. Other studies have explored the causal relations

among these identity-conferring moral traits (Chen, Urminsky, & Bartels, 2016), their role in social relationships (Heiphetz, Strohminger, & Young, 2017), and their bearing on debates in the philosophy of personal identity (Prinz & Nichols, 2016).

Direction of change

Strohminger and Nichols (2014, p. 169) also speculated that had Phineas Gage's injury (the tamping rod shot through his skull) merely eliminated his memory for how to lay down railroad ties, it seems likely his friends would have seen the same old Gage shining through beneath his impairment." But Gage didn't just lose his memories. Before the accident, Gage was kind and hard-working, but after the accident, he was reported to have become cruel and impulsive. So much so that "he was no longer Gage". This story is probably inaccurate (Macmillan, 2000), but it has long been treated as a paradigmatic case of identity change (e.g., Damasio, 1994).

Kevin Tobia (2015) uses Gage's story to reveal another surprising and important feature of judgements about personal identity. In one condition, participants saw the standard case of Phineas Gage, where he was kind before the accident, but cruel afterwards. That is, Gage *deteriorated*. In another condition, holding the magnitude of the change constant, participants saw a case where Gage was cruel before the accident, but kind afterward. That is, Gage *improved*. In both conditions, Tobia asked participants to judge whether Phineas Gage was the same person as before the accident.

The results indicated that Gage was less likely to be judged as identical to his pre-accident self when the change was in a "bad" direction (deteriorating from kind to cruel) than when the change was in a "good" direction (improving from cruel to kind) even when the amount of change was the same. These results suggest that judgments of identity change are not solely a function of the *magnitude* of the change, but are also importantly related to the *direction* of the change. When people are perceived as deteriorating (and especially when they are perceived to deteriorate morally), they are judged to be more of a different person than when they improve or change in a positive direction.

Some ethics of DBS

The psychological research on the moral self and the direction of change reveals how people actually make judgments of personal identity. Because those common judgments might be dismissed as mistaken, surveys cannot settle the metaphysical issue of when identity really does change.

Nonetheless, this scientific research can guide "an explication of what we mean when judging that someone has become 'another person'" (Witt et al., 2013, p. 501), which is a central task for neuroethicists in debates about DBS. In this section, we will discuss some lessons of the psychological research for personal identity and the ethics of DBS.

Two modest proposals

Our first proposal is to do more experiments. Neuroethicists involved in the CIT debate should adapt research paradigms from the moral self literature to explore what

affects our judgments of personal identity after DBS. Scenarios about brain transplants could easily be replaced with scenarios about DBS. In addition to measures of changes to morality, apathy, memory, and personality, new experiments could include other measures of concern to neuroethicists, such as core or periphery attitudes. One precedent in this direction is [Klein et al. \(2016\)](#), which asked about responsibility, identity, privacy, security, and enhancement after closed-loop DBS. Future research should also include measures of moral beliefs, motivations, emotions, actions, etc. This research would benefit neuroethics by supplementing a priori theorizing about identity change with data about what people actually think about identity change. It would also benefit psychological research on identity change by testing theories with consequential, real-life scenarios.

Our second proposal is to build more nuanced psychometrics to assess the kinds of changes DBS patients undergo. This need is recognized by each side of the CIT debate, as we saw in section “Clinical uses of DBS.” Because people tend to see moral traits as identity-conferring, as the moral self research shows, measuring changes to moral functioning pre- and post-DBS should be a priority for neuroethicists concerned with identity changes brought about by DBS and other forms of neurostimulation. While this suggestion is modest, conducting the actual work is much more ambitious. Developing and validating new measures involves multiple, iterative processes.

Importantly, this proposed research will need to be sensitive to cross-cultural differences in conceptions of the self and moral values. Future work on the ethics of DBS would also do well to engage the vast literature in psychology which has studied how these conceptions vary across cultures. For example, classic studies in cultural psychology have explored differences between independent versus interdependent conceptions of the self (e.g., [Markus & Kitayama, 1991](#)) and differences between individualistic and collectivistic cultures (e.g., [Triandis, 1989](#)). In a recent review of this research program, Markus and Kitayama (2010, p. 421) note that the study of cultural influence on self-concepts “has led to the realization that people and their sociocultural worlds are not separate from one another.” Thus, the potential threats to identity posed by DBS (or other interventions) should be understood with reference to specific cultural contexts. What might seem like a trivial aspect of the self in one cultural context could be quite profound in another cultural context.

Another growing body of recent research has looked at cultural variation in moral values specifically (see [Graham, Meindl, Beall, Johnson, & Zhang, 2016](#) for a review). Insofar as morality is perceived to be especially important for identity, then we would also expect perceived identity changes to vary as a function of sociomoral context. Again, what might seem like a minor change to a patient’s moral functioning in one cultural context could be perceived quite differently in another.

As DBS technology continues to advance and spread, and as indications for DBS continue to proliferate, these cultural considerations about the self and morality will become increasingly important. It should be noted that in terms of neurostimulatory techniques, DBS is among the most expensive and invasive. We do not think this makes the ethical issues any less pressing in a global context, however. Other techniques, such as transcranial magnetic stimulation (TMS) or transcranial direct-current stimulation (TCDS), which are cheaper and less invasive, may raise some of the same

concerns considered here. While the present chapter is a contribution to the growing literature about the ethics of DBS specifically, the ethical issues we raised and the empirical evidence we presented should be applicable to less expensive neurotechnologies which may be more likely than DBS to spread around the globe.

Cases of DBS

The moral self literature also throws new light on the case reports in our introduction. [Schüpbach et al. \(2006\)](#) and [Klein et al. \(2016\)](#) highlight the importance of distinguishing between DBS for motor indications (PD) and psychiatric indications (OCD or TRD). The patients from [Klein et al. \(2016\)](#) underwent DBS for OCD or TRD. One reported “I’m me without depression.” Another claimed to be “back to sort of a baseline ... back to yourself.” In contrast, the journalist described in [Schüpbach et al. \(2006\)](#) received DBS for PD and reported that she had “lost her passion,” and “didn’t feel like herself anymore.” Why does one patient feel more like her real self while the other feels more like a new person? Perhaps because the latter deteriorates in motivation. The moral self literature suggests that people tend to view deterioration as more disruptive to identity than improvements and changes to moral functioning and desires (such as losing passions, becoming apathetic, etc.) as more disruptive to identity than changes to basic cognitive or perceptual faculties.

The journalist who received DBS for PD changed in the ways and the direction that reduce judgments of identity persistence, whereas the patients who received DBS for OCD and TRD did not change in those ways, since they improved in motivation. They are now energetic instead of lethargic and exhibit a range of emotions instead of blunted affect. Thus, the moral self research may help to explain this contrast in personal identity judgments after DBS (cf. [Nyholm & O’Neill, 2016](#), p. 650).

Although these cases distinguish judgments about personal identity by patients who receive DBS, judgments by other people matter, too. In a standard PD case, the motor benefits (e.g., reduced tremor) are thought to outweigh the cognitive, motivational, and affective costs (e.g., apathy and decreased verbal fluency) *for the patient*. The case reports often leave unclear how these changes affect others, including children and elderly dependents. Imagine how young children are affected if a parent goes in for surgery and what returns seems to be a different person (or if the same happens to a care-giver for an elderly person with dementia). These changes are bound to produce confusion and dismay. They loved this parent (or caregiver) and had learned how to deal with that individual. Now they have to relearn a lot, and they might not understand why or how the change happened. Dependents can be hurt even more if the parent (or caregiver) becomes morally worse or apathetic. The dependent used to trust their parent (or caregiver), but now they find that the new person is untrustworthy. The patient’s apathy can be contagious. Lethargy can also signal lack of love, for example, if the new person refuses to play or talk with the dependent.

Apathy post-DBS might even lead to violations of moral duties, for example, if the new person breaks promises or neglects the dependent. These particular concerns do not arise with DBS for TRD in the same way—much the reverse. When a depressed parent becomes happier and less lethargic, their kids may benefit. The same applies to DBS for OCD if it has no side effects like apathy.

In any case, the point here is that DBS sometimes does have negative effects on dependents and close others, such as family and friends. Neuroethicists and doctors should take into consideration these effects of DBS on people other than the patient. They need to ask: Should doctors should insert DBS when they know that the family will be harmed? Should they wait until kids get old enough to understand and cope better? Should doctors inform patients before surgery of these possible negative side effects on their loved ones?

Closed-loop DBS

Additional questions arise for closed-loop DBS if the patient controls the level of stimulation. Should parents be encouraged to reduce or turn off their DBS when around their children? It might actually be preferable for the parent as well as the child for the patient to feel genuinely excited about going to their child's basketball game, even if it meant that the tremors would return for a while.

More generally, neuroethicists need to ask how much control patients should have. The values of autonomy or freedom speak in favor of letting patients adjust their DBS devices as they wish. However, mistakes as well as intentional abuses are likely, if turning devices higher produces mania or euphoria. Should doctors enable patients to control the level of stimulation after DBS for PD? For TRD? For OCD? As DBS technology progresses, these questions about user control will become increasingly important.

Culture and context

These questions all arise in a particular cultural context, and that matters. In some but far from all cultures, alternative resources are readily available to reduce harms to dependents after a DBS patient becomes apathetic. This context might affect our answer to the question of whether a particular patient with PD should be treated with DBS.

Classical issues in biomedical ethics are also raised in interesting ways in the context of DBS. For example, culture can influence expectations about the doctor's role. In some cultures, a doctor works for the patient and is supposed to do whatever is in the best interest of the individual patient without concern for the patient's family or friends (except to the extent that their welfare affects the patient). In other cultures, a doctor works for society and is expected to do what is in the interest of society as a whole or at least all significantly affected parties, including the patient's family and friends. In these and other ways, cultures differ on how much value they place on individual autonomy when it conflicts with social welfare. Those differences are bound to affect answers to questions about the ethics of DBS.

More questions

We have asked only a small sample of the ethical questions raised by DBS. Here are a few more: Which policies should hospitals adopt about which patients should get DBS? When should doctors and lawyers respect advance directives given before inserting DBS if the patient has different values and even seems like a new person after

DBS? Should we allow DBS trials in the developing world if DBS is likely to turn the patient into a different person (in addition to the usual risks)? Should patients in developed countries have the “right to try” DBS before official approval, despite the risk that the person after DBS might wish that the stimulator had not been inserted? Should prisons be allowed to offer inmates reduced sentences if they consent to insertion of DBS aimed at reducing their violent tendencies? Many of these questions regard far-out fictions, perhaps fortunately. Nonetheless, we need to get prepared to answer these and many more ethical questions about what DBS makes possible.

References

- Alonso, P., Cuadras, D., Gabriëls, L., Denys, D., Goodman, W., Greenberg, B. D., et al. (2015). Deep brain stimulation for obsessive-compulsive disorder: A meta-analysis of treatment outcome and predictors of response. *PLoS One*, *10*(7), e0133591.
- Bari, A. A., Mikell, C. B., Abosch, A., Ben-Haim, S., Buchanan, R. J., Burton, A. W., et al. (2018). Charting the road forward in psychiatric neurosurgery: Proceedings of the 2016 American Society for Stereotactic and Functional Neurosurgery workshop on neuromodulation for psychiatric disorders. *Journal of Neurology, Neurosurgery, and Psychiatry*, *89*(8), 886–896.
- Baylis, F. (2013). “I am who I am”: On the perceived threats to personal identity from deep brain stimulation. *Neuroethics*, *6*(3), 513–526.
- Benabid, A. L., Pollak, P., Louveau, A., Henry, S., & De Rougemont, J. (1987). Combined (thalamotomy and stimulation) stereotactic surgery of the VIM thalamic nucleus for bilateral Parkinson disease. *Stereotactic and Functional Neurosurgery*, *50*(1–6), 344–346.
- Bergfeld, I. O., Mantione, M., Hoogendoorn, M. L., Ruhé, H. G., Notten, P., van Laarhoven, J., et al. (2016). Deep brain stimulation of the ventral anterior limb of the internal capsule for treatment-resistant depression: A randomized clinical trial. *JAMA Psychiatry*, *73*(5), 456–464.
- Chen, S. Y., Urminsky, O., & Bartels, D. M. (2016). Beliefs about the causal structure of the self-concept determine which changes disrupt personal identity. *Psychological Science*, *27*(10), 1398–1406.
- Damasio, A. (1994). *Descartes’ error*. Putnam Publishing.
- De Haan, S., Rietveld, E., Stokhof, M., & Denys, D. (2017). Becoming more oneself? Changes in personality following DBS treatment for psychiatric disorders: Experiences of OCD patients and general considerations. *PLoS One*, *12*(4), e0175748.
- Dougherty, D. D., Rezai, A. R., Carpenter, L. L., Howland, R. H., Bhati, M. T., O’Reardon, J. P., et al. (2015). A randomized sham-controlled trial of deep brain stimulation of the ventral capsule/ventral striatum for chronic treatment-resistant depression. *Biological Psychiatry*, *78*(4), 240–248.
- Earp, B. D., Skorborg, J. A., Everett, J. A., & Savulescu, J. (2019). Addiction, identity, morality. *AJOB Empirical Bioethics*, *10*(2), 136–153.
- Focquaert, F., & DeRidder, D. (2009). Direct intervention in the brain: Ethical issues concerning personal identity. *Journal of Ethics in Mental Health*, *4*, 1–7.
- Gardner, J. (2013). A history of deep brain stimulation: Technological innovation and the role of clinical assessment tools. *Social Studies of Science*, *43*(5), 707–728.
- Glannon, W. (2009). Stimulating brains, altering minds. *Journal of Medical Ethics*, *35*(5), 289–292.

- Goddard, E. (2017). Deep brain stimulation through the “lens of agency”: Clarifying threats to personal identity from neurological intervention. *Neuroethics*, *10*(3), 325–335.
- Goering, S., Klein, E., Dougherty, D. D., & Widge, A. S. (2017). Staying in the loop: Relational agency and identity in next-generation DBS for psychiatry. *AJOB Neuroscience*, *8*(2), 59–70.
- Graham, J., Meindl, P., Beall, E., Johnson, K. M., & Zhang, L. (2016). Cultural differences in moral judgment and behavior, across and within societies. *Current Opinion in Psychology*, *8*, 125–130.
- Hacker, M. L., Tonascia, J., Turchan, M., Currie, A., Heusinkveld, L., Konrad, P. E., et al. (2015). Deep brain stimulation may reduce the relative risk of clinically important worsening in early stage Parkinson's disease. *Parkinsonism & Related Disorders*, *21*(10), 1177–1183.
- Hariz, M., Blomstedt, P., & Zrinzo, L. (2013). Future of brain stimulation: New targets, new indications, new technology. *Movement Disorders*, *28*(13), 1784–1792.
- Heiphetz, L., Strohminger, N., Gelman, S. A., & Young, L. L. (2018). Who am I? The role of moral beliefs in children's and adults' understanding of identity. *Journal of Experimental Social Psychology*, *78*, 210–219.
- Heiphetz, L., Strohminger, N., & Young, L. L. (2017). The role of moral beliefs, memories, and preferences in representations of identity. *Cognitive Science*, *41*(3), 744–767.
- Hickey, P., & Stacy, M. (2016). Deep brain stimulation: A paradigm shifting approach to treat Parkinson's disease. *Frontiers in Neuroscience*, *10*, 173. <https://doi.org/10.3389/fnins.2016.00173>.
- Holtzheimer, P. E., Husain, M. M., Lisanby, S. H., Taylor, S. F., Whitworth, L. A., McClintock, S., et al. (2017). Subcallosal cingulate deep brain stimulation for treatment-resistant depression: A multisite, randomised, sham-controlled trial. *The Lancet Psychiatry*, *4*(11), 839–849.
- Kessler, R. C., & Bromet, E. J. (2013). The epidemiology of depression across cultures. *Annual Review of Public Health*, *34*, 119–138.
- Kisely, S., Hall, K., Siskind, D., Frater, J., Olson, S., & Crompton, D. (2014). Deep brain stimulation for obsessive-compulsive disorder: A systematic review and meta-analysis. *Psychological Medicine*, *44*(16), 3533–3542.
- Klein, E., Goering, S., Gagne, J., Shea, C. V., Franklin, R., Zorowitz, S., et al. (2016). Brain-computer interface-based control of closed-loop brain stimulation: attitudes and ethical considerations. *Brain-Computer Interfaces*, *3*(3), 140–148.
- Kraemer, F. (2013a). Me, myself and my brain implant: Deep brain stimulation raises questions of personal authenticity and alienation. *Neuroethics*, *6*(3), 483–497.
- Kraemer, F. (2013b). Authenticity or autonomy? When deep brain stimulation causes a dilemma. *Journal of Medical Ethics*, *39*(12), 757–760.
- Kramer, P. D. (1993). *Listening to Prozac: The landmark book about anti-depressants and the remaking of the self*. Penguin Books.
- Kurtis, M. M., Rajah, T., Delgado, L. F., & Dafsari, H. S. (2017). The effect of deep brain stimulation on the non-motor symptoms of Parkinson's disease: a critical review of the current evidence. *npj Parkinson's Disease*, *3*, 16024.
- Lipsman, N. I. R., & Glannon, W. (2013). Brain, mind and machine: What are the implications of deep brain stimulation for perceptions of personal identity, agency and free will? *Bioethics*, *27*(9), 465–470.
- Liu, Y., Li, W., Tan, C., Liu, X., Wang, X., Gui, Y., et al. (2014). Meta-analysis comparing deep brain stimulation of the globus pallidus and subthalamic nucleus to treat advanced Parkinson disease: a review. *Journal of Neurosurgery*, *121*(3), 709–718.

- Macmillan, M. (2000). *An odd kind of fame: Stories of Phineas gage*. Cambridge, MA: MIT Press.
- Malone, D. A., Jr., Dougherty, D. D., Rezai, A. R., Carpenter, L. L., Friehs, G. M., Eskandar, E. N., et al. (2009). Deep brain stimulation of the ventral capsule/ventral striatum for treatment-resistant depression. *Biological Psychiatry*, 65(4), 267–275.
- Macerollo, A., & Deuschl, G. (2018). Deep brain stimulation for tardive syndromes: Systematic review and meta-analysis. *Journal of the Neurological Sciences*, 389, 55–60.
- Markus, H. R., & Kitayama, S. (1991). Culture and the self: Implications for cognition, emotion, and motivation. *Psychological Review*, 98(2), 224–253.
- Markus, H. R., & Kitayama, S. (2010). Cultures and selves: A cycle of mutual constitution. *Perspectives on Psychological Science*, 5(4), 420–430.
- Müller, S., Bittlinger, M., & Walter, H. (2017). Threats to neurosurgical patients posed by the personal identity debate. *Neuroethics*, 10(2), 299–310.
- Munhoz, R. P., Picillo, M., Fox, S. H., Bruno, V., Panisset, M., Honey, C. R., et al. (2016). Eligibility criteria for deep brain stimulation in Parkinson's disease, tremor, and dystonia. *Canadian Journal of Neurological Sciences*, 43(4), 462–471.
- National Institute of Neurological Disease and Stroke. (2017). Retrieved from: <https://www.ninds.nih.gov/Disorders/All-Disorders/Deep-Brain-Stimulation-Parkinsons-Disease-Information-Page>.
- Northoff, G. (2004). The influence of brain implants on personal identity and personality—A combined theoretical and empirical investigation in neuroethics. In T. Schramme & J. Thome (Eds.), *Philosophy and psychiatry* (pp. 326–342). Berlin: Walter de Gruyter.
- Nuttin, B., Cosyns, P., Demeulemeester, H., Gybels, J., & Meyerson, B. (1999). Electrical stimulation in anterior limbs of internal capsules in patients with obsessive-compulsive disorder. *Lancet*, 354(9189), 1526.
- Nyholm, S. (2017). Is the personal identity debate a “threat” to neurosurgical patients? A reply to Müller et al. *Neuroethics*, 1–7. <https://doi.org/10.1007/s12152-017-9337-4>.
- Nyholm, S., & O'Neill, E. (2016). Deep brain stimulation, continuity over time, and the true self. *Cambridge Quarterly of Healthcare Ethics*, 25(4), 647–658.
- Okun, M. S., Fernandez, H. H., Wu, S. S., Kirsch-Darrow, L., Bowers, D., Bova, F., et al. (2009). Cognition and mood in Parkinson's disease in subthalamic nucleus versus globus pallidus interna deep brain stimulation: The COMPARE trial. *Annals of Neurology*, 65(5), 586–595.
- Pagonabarraga, J., Kulisevsky, J., Strafella, A. P., & Krack, P. (2015). Apathy in Parkinson's disease: Clinical features, neural substrates, diagnosis, and treatment. *Lancet Neurology*, 14, 518–531.
- Pugh, J., Maslen, H., & Savulescu, J. (2017). Deep brain stimulation, authenticity and value. *Cambridge Quarterly of Healthcare Ethics*, 26(4), 640–657.
- Prinz, J. J., & Nichols, S. (2016). Diachronic identity and the moral self. In J. Kiverstein (Ed.), *The Routledge handbook of philosophy of the social mind* (pp. 449–464). New York: Routledge.
- Roskies, A. L. (2002). Neuroethics for the new millennium. *Neuron*, 35, 21–23.
- Schechtman, M. (2010). Philosophical reflections on narrative and deep brain stimulation. *The Journal of Clinical Ethics*, 21(2), 133–139.
- Schechtman, M. (2007). *The constitution of selves*. Cornell University Press.
- Schermer, M. (2009). Changes in the self: The need for conceptual research next to empirical research. *The American Journal of Bioethics*, 9(5), 45–47.
- Schüpbach, W. M., Rau, J., Knudsen, K., Volkmann, J., Krack, P., Timmermann, L., et al. (2013). Neurostimulation for Parkinson's disease with early motor complications. *New England Journal of Medicine*, 368(7), 610–622.

- Schüpbach, M., Gargiulo, M., Welter, M., Mallet, L., Béhar, C., Houeto, J. L., et al. (2006). Neurosurgery in Parkinson disease a distressed mind in a repaired body? *Neurology*, *66*(12), 1811–1816.
- Strohming, N., & Nichols, S. (2014). The essential moral self. *Cognition*, *131*(1), 159–171.
- Synofzik, M., & Schlaepfer, T. E. (2008). Stimulating personality: Ethical criteria for deep brain stimulation in psychiatric patients and for enhancement purposes. *Biotechnological Journal*, *3*, 1511–1520.
- Tobia, K. P. (2015). Personal identity and the Phineas gage effect. *Analysis*, *75*(3), 396–405.
- Triandis, H. C. (1989). The self and social behavior in differing cultural contexts. *Psychological Review*, *96*(3), 506–520.
- Witt, K., Kuhn, J., Timmermann, L., Zurowski, M., & Woopen, C. (2013). Deep brain stimulation and the search for identity. *Neuroethics*, *6*(3), 499–511.

Further reading

National Institute of Mental Health. (2017). Retrieved from: <https://www.nimh.nih.gov/health/statistics/major-depression.shtml>.