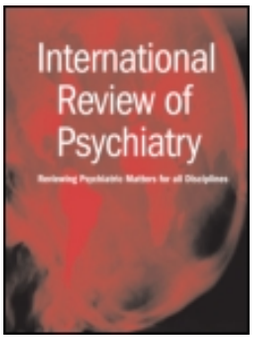

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Deep brain stimulation, personal identity and policy

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Abstract
A range of implantable brain-interfacing devices (IBIDs) is currently in use and development for the treatment of movement disorders and disorders of mood, behaviour and thought. These include cochlear implants, deep brain stimulation (DBS), prosthetic limbs, and optogenetic interventions (the combined use of genetics and optics to control individual cells). While implantable non-brain devices, such as implantable cardioverter defibrillators, began receiving US Food and Drug Administration approval in 1980, the development of IBIDs is recent, with the approval of DBS for Parkinson's disease in 1997. The expansion in use of IBIDs from neurological to psychiatric conditions is even more recent, with current trials underway for a range of disorders including depression, OCD, addiction, Alzheimer's disease and Tourette's syndrome. Emerging applications of existing IBIDs and new devices in development differ from currently approved devices and applications in two potentially crucial ways: 1) They target conditions traditionally seen as psychiatric; and/or 2) They target and modify functions or traits tied closely to agency, personal identity and personhood. As such, understanding patients' and caregivers' conceptions of personal identity in the context of disease and treatment is important not only for the informed consent process, but also for questions of public policy.

Introduction

A man, married fifty years, receives deep brain stimulation (DBS) to treat his Parkinsonian tremor. An avowed curmudgeon, his tremor is dramatically improved after treatment, but so is his dour demeanour. He is now uniformly elated, persistently cheerful, though not in a way that is responsive to life's ups and downs. He is 'cured', yet changed. Unfortunately, his wife now finds him insufferable; this is not the man she married. Turn off the device, he is 'himself', and tremulous. Turn on the device, his wife does not 'know him'. This anecdote raises many important ethical and practical questions, including whether dramatic personality change should be treated as a medical problem, and whether and how such changes affect patients' sense of self or their relationships with loved ones. Yet we have few data and no clear framework for addressing these issues.

Arguably, how scientists design their studies, how patients weigh their options, and how society views and oversees implantable brain-interfacing devices such as DBS are influenced by information about how one's sense of self may be changed during treatment, and the meaning of that change to patients and their loved ones.

Background

A range of implantable brain-interfacing devices (IBIDs) is currently in use and development for the treatment of movement disorders and disorders of mood, behaviour and thought (MBT). These include retinal implants, cochlear implants, DBS (e.g. Tye et al., 2009; Ward, et al., 2010), prosthetic limbs (Defense Advanced Research Projects Agency, 2011), and optogenetic interventions (the combined use of genetics and fibre-optics to control individual cells) (Deisseroth et al., 2006). While implantable non-brain devices, such as implantable cardioverter defibrillators (ICDs), phrenic nerve stimulators, and bone stimulators, began receiving US Food and Drug Administration (FDA) approval in 1980, the development of IBIDs is recent, with the approval of DBS for Parkinson's disease (PD) in 1997. The expansion in use of IBIDs from neurological to psychiatric conditions is even more recent, with DBS for obsessive–compulsive disorder (OCD) granted limited FDA approval through a humanitarian device exemption in 2009. DBS trials are underway for a range of disorders including depression, OCD, addiction, Alzheimer's disease and Tourette's syndrome (ClinicalTrials.gov).

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Emerging applications of existing IBIDs and new devices in development differ from currently approved devices and applications in two potentially crucial ways: 1) They target conditions traditionally seen as psychiatric (Tye et al., 2009; Ward et al., 2010); and/or, 2) They target functions or traits tied closely to agency, personal identity and personhood (Appleby et al., 2007; Bell et al., 2009; Brand 2009; Clausen 2008; Glannon 2009; Rabins et al., 2009; Synofzik & Schlaepfer, 2011). Also, while existing IBIDs are likely the harbingers of a future in which direct, mechanical interventions with the brain are not remarkable, they are also linked to the disturbing history of abuse of the mentally ill by proponents of an earlier surgical intervention with the brain – lobotomy – in the 1940s (Valenstein, 1986).

Critically, and despite ongoing work on IBIDs, there is no consensus about what counts as a benefit or harm resulting from the use of these devices, with respect to sense of self: change in personality or self may be considered benefit, harm, or not at all, depending on the condition being treated, the nature and degree of change, and the outcome measures used. If the only outcomes measured following DBS for PD are tremor and activities of daily living (ADL), our curmudgeon above had a very successful surgery. However, these measures do not seem to capture the full story (Mathieu et al., 2011; Müller & Christen, 2011).

Personal identity – how individuals define themselves, how they view their place in the world and their relationships to those they love – though subjective and difficult to measure, is important not only for individual lives and decisions, but also because answers to questions about personal identity influence our views of a person's responsibilities and our obligations to that person.

However, some have claimed that personal identity cannot be an ethical criterion used in the evaluation of IBIDs precisely because changes in identity are sometimes the goal of treatment (Clausen, 2011; Synofzik & Schlaepfer, 2008, 2011). This claim oversimplifies the concept of personal identity and discounts its importance. This claim implies a view of identity as a collection of symptoms to be treated, rather than a constellation of characteristics, values and the experiential sense of who one fundamentally is as a person. There is a difference between recovering from illness and being transformed, between becoming oneself again and becoming someone else (e.g. Kramer, 1997). It has been further suggested that considering changes in personal identity in the context of DBS can 'unnecessarily complicate weighing risks and benefits' (Clausen, 2011, p. 497). On the contrary, one cannot adequately weigh risks and benefits without knowing 1) the range of possible outcomes, including those related to personal identity and 2) how patients and their families perceive and value those outcomes.

We have been implanting devices in patients for decades. We have been modulating patients' moods for decades, behaviourally, pharmacologically and with interventions such as electroconvulsive therapy (ECT). How different is DBS really? Intuitively, this feels different, but is it? How do patients perceive changes in personal identity – be they intended or unintended, welcome or unwelcome – at the flip of a switch? How ought we to think about a technology or a set of technologies that has the power to intervene in something as central to the experience of being human as one's sense of self? The best way to inform these questions is to ask those involved in the research, in particular the patients, subjects and families contemplating and living with IBIDs.

Implantable Devices

The medical community and certain patient populations have a great deal of experience with implanted devices. Bone, spinal cord and phrenic nerve stimulators, as well as ICDs were all approved for use by the FDA in the 1980s. Cochlear implants and left ventricular assist devices (LVADs) were approved in the 1990s. While not used as treatments for neurological or psychiatric conditions, these devices do become part of the body and interface with the nervous system to lesser or greater degrees.

An ICD is a small device that is implanted in the chest or abdomen, and connected to leads that end in or on the heart. The devices are used in patients at risk of recurrent, sustained and potentially fatal irregular heart rhythms that can lead to sudden cardiac arrest and death. An ICD monitors heart rhythms, identifies irregular rhythms, and delivers electrical shocks directly to the heart to re-establish a regular rhythm. Modern devices can also act as pacemakers, as necessary. The electrical stimulus that is delivered in response to detected arrhythmias can be strong and painful. Anxiety and depression are common among these patients, and may be associated with receiving higher numbers of shocks (Sears & Conti, 2002). Furthermore, some patients with ICDs who have received shocks also report a lower quality of life, due largely to conditioned avoidance of activities they believe are likely to induce a shock (Sears & Conti, 2002).

A cochlear implant is a small, multi-part electrical device that can help those with profound deafness or hearing loss detect sound. The device is composed of an external component, placed behind the ear, including a microphone, speech processor and transmitter, and an implanted component, which consists of a receiver/stimulator and an array of electrodes

that communicates with the auditory nerve. As of 2009, over 41,000 adults and 25,000 children had received implants in the USA, (http://www.nidcd.nih.gov/health/hearing/coch.html). While implants do not restore normal hearing, they can help recipients hear enough to engage in a conversation without the use of sign language or lip-reading.

Aside from indication, how are IBIDs different from such prior implantable devices? Intuitively, the experience of having an implantable device in the brain seems qualitatively different. But intuitions are often misleading; similar claims were made prior to the development of heart transplants, and did not materialize. It may well be that people who have implants that can intervene with their mood, behaviour or thought have similar views to those with DBS for PD or implants that interface with their hearts (e.g. ICDs), with respect to personal identity and their relationship to their device. If that is the case, we may conclude that new devices are simply a logical extension of earlier practices, suggesting that changes in personal identity are not something that we need to worry about more with IBIDs than with other sorts of implantable devices. However, it seems plausible that those being implanted with the device and others (loved ones, the legal system, the medical system) will perceive IBIDs differently. Ultimately, the answer to this question must come from the experiences of patients and others deeply involved (Mathieu et al., 2011).

Along with an extensive history of the use of implantable devices in medicine, we also have experience with DBS for movement disorders, with over 80,000 patients receiving one or more deep brain stimulators since FDA approval. DBS interfaces with the brain, but when used for PD, is not intended to influence mood, behaviour or thought, although it sometimes happens. While there are few data about unintended affective changes in the treatment of PD with DBS (Appleby et al., 2007; Bronstein et al., 2011), it is well known that depression and impulsivity can be associated with the treatment (Bronstein et al., 2011). Every surgeon has anecdotes, but such changes are not routinely measured, nor are they reported in the literature (Appleby et al., 2007). Changes can be dramatic, as with the curmudgeon, or less so, as with mild depression. A colleague has had a number of DBS PD patients report that they feel 'different' in an experiential or ideational way (personal communication, Peter Rabins). Of note, some of these changes can also happen in pharmacologically managed patients with PD, but the effects are not as immediate as they are with DBS.

Looking forward, IBIDs currently at the research stage include artificial limbs that interface directly with the brain, and optogenetic research, which combines genetic manipulation and fibre-optics to control individual cells in a way that is similar to DBS, but much more precise. The Defense Advanced Research Projects Agency's (DARPA) Human-Assisted Neural Devices (HAND) and Revolutionizing Prosthetics programmes were established to improve artificial limbs for military amputees (http://www.darpa.mil). In 2010 they awarded a contract to develop and take to clinical trials a prosthetic arm that uses an IBID to allow the recipient to control the arm with her thoughts (http://www.jhuapl.edu/newscenter/pressreleases/2010/100714.asp). Optogenetics is in the very early stage of development, and is currently being used in rodent models to interrogate neural circuits (Deisseroth et al., 2006). However, it has the potential to become a powerful tool for human neuromodulation through direct, real-time control of specific cells in the brain.

Personal identity

Questions related to the nature and meaning of personal identity are among those that are unsettled and highly contested in philosophy. One way to approach defining personal identity is through the enumeration of the criteria required to claim that person A and person B (perhaps at ages 20 and 50) are in fact the same person. Physical criteria (for example, through finger prints or the interrogation of DNA samples from both people) are one way we may attempt to establish identity. Psychological criteria (for example, does the 50 year old have memories of being the 20 year old) are another way of making a claim of identity in this case. Criteria of this sort are frequently tested by philosophers through cleverly designed thought experiments, intended to probe the experimenter for intuitions about the identity of two beings. For example, we might be asked to imagine ourselves in the distant future, when interventions such as brain transplants are possible. You and your brother are kidnapped by a mad scientist, and your brains switched: your brain in the skull of your brother, and vice versa, both fully functional in their new homes. Following surgery, do you still exist? If so, in which body do you reside? If, instead of receiving your brother's brain, you receive a precise copy of your own brain, such that both you and the body of your brother are governed by identical brains, now where are 'you' following surgery? Different philosophers will answer questions about these scenarios differently, depending on their theory of personal identity, and its relationship to or reliance on physical and psychological criteria.

However, DBS and other IBIDs do not raise concerns about personal identity in this sense (i.e. numerical identity); that is, the problem is not that a patient might turn into a different physical

person. Rather IBIDs raise concerns for a concept of personal identity based on narrative continuity (e.g. Mathews et al., 2009; Schechtman, 1996), with the stipulation that we can confirm physical identity. Furthermore, this sense of personal identity seems most in line with lay understandings of the self. On this view, personal identity requires that one have a sense of oneself as a continuous being over time, with memories and reasons and explanations for the changes that have occurred. Changes in identity are anticipated, but it is expected that those changes can be justified by reasons, and supported by facts. As Maura Tumulty has written, 'being a self is a job of work' (Mathews et al., 2009, p. 29). Questions about personal identity arise when a person seems to be losing the capacity to engage in that work.

Both within philosophy and in everyday life, personal identity is fundamental to how individuals understand themselves and those around them. Many people have had the experience of a family member or friend whose identity has been so altered by disease, injury or drugs that they appear to have become a different person altogether. Clinicians, including psychiatrists, psychologists and neurologists, encounter daily patients whose sense of self is diminished or altered by disease and perhaps experience. Philosophers attempt to answer questions including those related to the criteria for personal identity, when and how personal identity can be altered or wholly changed, and the meaning of such changes.

Among the reasons that the construct of personal identity is important is that it influences our views of an individual's responsibilities and our responsibilities to that individual. For example, within a marriage, if one partner becomes so changed by disease that he is no longer, in the wife's view, the person she married, the wife's views may change with regard to her obligations to honour the promises she made to the prior and no longer present man who was her husband.

Personal identity in the context of disease

While the case of the curmudgeon raises very real interpersonal issues, additional cases highlight other complexities. For example, one reported case (Leentjens et al., 2004) describes a 62-year-old man who, three years after receiving DBS for PD, developed uncontrollable mania. With the stimulator off, his motor symptoms were debilitating, but he was competent. With the stimulator on, his motor symptoms were controlled, but he was manic and incompetent. Ultimately, the man had to choose between a nursing home, where he would be bedridden but coherent, and a psychiatric ward, where he would be mobile, but manic. He chose the latter.

With disease, as with interventions, there are differences in the kinds of changes that occur and in how patients and caregivers interpret and value of those changes. For example, individuals suffering with early Alzheimer's and depression often recognize the changes that are occurring, and feel a relationship to and continuity with those changes. In contrast, in frontotemporal dementia and some individuals with schizophrenia, this recognition and relationship are usually absent. Additionally, in the treatment of disorders of MBT, whether it is by pharmaceuticals or device, changes in affect are the goal of treatment, making it potentially difficult to tease out desired affective changes from undesirable changes in personal identity (Müller & Christen, 2011).

In the context of mental illness and its treatment with psychotropic drugs, clinicians, patients and caregivers have experienced, watched and studied the changes in personal identity. Karp (1994) conducted interviews with 20 people with depression, and outlined the stages of the disease from distress, to the sense that 'something's wrong', to crisis, to a narrative shift within the patient to a disease identity, and finally, hopefully, another shift that allows the patient to identify the depression as something from which she or he can emerge. Furthermore, treatment modality aside, the condition itself (e.g. depression, OCD) has profound effects on personal identity, which must be acknowledged. While there are few to no data in the literature about medically managed psychiatric patients' views of personal identity and the effects of medication on sense of self, many memoirs describe the experience of living with psychiatric disease and the related changes in personal identity that can and do occur (Jamison, 1995; Kramer, 1997; Slater, 1998).

Do individuals receiving medical management for psychiatric conditions view changes in personal identity as a result of treatment differently than those receiving DBS for the same conditions? It certainly seems plausible that an IBID might be perceived differently from medication or psychotherapy. For example, the potential permanence of an implantable device that becomes part of the body and acts on the body may be conceptualized and experienced differently than the receiving and taking of pills, or personal, active changes that a person experiences as involving choice. An IBID also requires much more interaction with and dependence on the medical system, since a highly qualified, interdisciplinary medical team is required for ongoing readjustment and monitoring of the device's (and the patient's) function, as well as to remove the device, if necessary. Finally, at least in the case of DBS, effects may be uniquely reproducible, reversible, and immediate – changes in personal identity at the flip of a switch.

How patients themselves work through questions of personal identity is critically relevant for the purposes of research and practice. Important and unexplored questions include those related to how people with implants (and their caregivers) view and define personal identity. What is a patient's experience of herself and her identity before and after the onset of illness, implantation and treatment? Are there differences in the ways patients with IBIDs and patients with other kinds of implants view personal identity and their relationship to their device? If there is a dramatic change in personal identity, is there narrative continuity? How do the patient's answers to these questions cohere with their caregivers' views? What if a patient's and the caregivers' views diverge? Does the rapid, reversible and reproducible nature of the change in the case of DBS matter? And finally, are there potential changes to personal identity – as defined by patients and caregivers – that would constitute unacceptable risks? Answers to these questions have real implications not only for patients and their families, but also for research, development and policy.

Implications for practice, research and policy

Constructs such as mood, behaviour and thought are often considered essential aspects of humanness. Therefore, it is crucial to understand the degree to which patients and their families perceive such changes as risks, and their assessment of the meaning of those risks in the context of their disease and everyday life. Changes such as those experienced by the curmudgeon and his wife are unlikely to be common, as they are not routinely reported in the literature, yet they deserve attention and have not been studied systematically. It is important to learn about and understand the range of changes currently experienced by patients and observed by clinicians and scientists; they can answer questions about how commonly such changes occur, and how they are commonly addressed (Mathieu et al., 2011). Such data are important for ongoing research and practice insofar as they demonstrate that current processes for informed consent and provision of resources are inadequate to account for the risk of unanticipated or unwelcome changes in personal identity. Such data are also important as research and development advance, insofar as they signal the need to incorporate patient-reported outcomes in this area, or to develop new physician-administered outcome measures to facilitate the collection of additional data in the course of research.

Data on patients' and caregivers' views of personal identity in the context of disease and treatment/intervention have implications for informed consent of ongoing research and current practice. For example, insofar as unanticipated or unwelcome changes in personal identity occur, they should be conceptualized as risks. Research can best illuminate how to communicate that risk. This research may, in fact, chart unexplored territory, since it is not clear that a risk of change in personal identity – due not to a disease process, but to mechanical intervention with the brain – would be understood and considered similarly to risks of bodily injury. In cases where a patient or subject has experienced dramatic personality change, there will be further questions. For example, if a person is 'competent', but their perception of self/narrative does not cohere with their caregivers' view, how should this be approached? If a clinician is caring for a patient who has experienced dramatic personality change in the context of DBS, do clinical conversations happen and are clinical decisions made with the stimulator on or off? Take the example of the man with PD who chose to be mobile, incompetent and committed – should his doctor periodically turn off the stimulator to have conversations with the competent, though tremulous man? And who decides: the patient? the clinician? the caregiver? (Mackenzie, 2011) What about agency and personal and legal responsibility in the absence of overt personality change, but the presence of problematic behaviours?

Parallel questions can be raised from the perspective of the policymaker at the institutional, professional or governmental level. Evaluation of new technologies is frequently conducted with some form of technology assessment, which is a process by which new technologies are studied and evaluated, and it is 'intended to enhance societal understanding of the broad implications of science and technology, and, thereby, to improve decision-making' (Sklove, 2010, p. vii). Governments and others use technology assessment to inform a range of decisions including the permissibility and scope of a technology's use, the development and adoption of practice guidelines and, in the case of health technology assessment, insurance coverage. Regardless of the model of technology assessment used (e.g. Bimber, 1996; Rodemeyer et al., 2005; Sklove, 2010; US Congress, 1982), or the level at which it is occurring, at the core of the practice is the weighing of risks and benefits. In order to weigh risks and benefits, it must be clear what outcomes fall into each of those categories, as well as where those categories fail to operate effectively, for example by missing important outcomes. Currently, in the context of IBIDs, we lack the necessary data to evaluate risks and benefits. Collecting these data are critical to informing and protecting patients and subjects who are candidates for existing and emerging IBIDs.

Conclusions

As highlighted in a recent article in *Health Affairs* (Fins et al., 2011), and a related article in the *New York Times* (Carey, 2011), even the top clinicians and scientists in the field of DBS for disorders of MBT disagree strongly about the appropriateness of various policies governing the technology. There have been multiple consensus statements issued (e.g. Bronstein et al., 2011; Kennedy et al., 2009; Rabins et al., 2009), indications for DBS are expanding, and precious little is settled within the science. Even a recent expert consensus statement on DBS for PD (Bronstein et al., 2011), despite over 14 years of experience with this surgery, lacked consensus around details of patient selection, in particular as related to psychiatric conditions. Furthermore, there is still debate about the best site within the brain to target for PD (Krack & Hariz, 2010), as well as for all disorders of MBT.

Patients and research subjects are better served when they and physicians/investigators share a common language for discussing the benefits and risks of available interventions. In order to take adequate account of the risks and benefits, particularly in the context of disorders of MBT, we may need to develop a framework for assessing IBIDs that is tailored specifically to the issues and concerns posed by this class of technologies. This would increase the likelihood of developing a comprehensive approach that would better identify the risks and benefits from the perspective of patients and families. Such a model would facilitate the identification and development of specific outcomes (either patient reported or clinically assessed) that should be monitored in the conduct of basic and translational research in the development of IBIDs. These, in turn, could aid in clinical, societal and policy decision-making. For example, collecting and evaluating data on changes in personal identity following intervention with an IBID, such as DBS, would enable a more robust and meaningful informed consent process that incorporates patients' views of personal identity and what counts as a risk or benefit in the context of such studies. If patients and caregivers do view changes in personal identity as a potential risk of DBS, this would signal the need for the development of consensus pre- and post-implantation measures to assess changes that rise to the level of concern, as defined by patients and caregivers. The identification of those personal identity-specific factors (e.g. personality type, behaviours, core inviolable beliefs) that are most important to patients may signal the need for the development of new metrics to facilitate pre- and post-implantation assessment, as well as standards for data collection and reporting. Going forward, such standards will be critical to permitting researchers and oversight bodies to monitor for and accurately describe the range of potential changes and the magnitude of risk, and their relationship to other variables (e.g. DBS target, individual neuroanatomy, device settings, comorbid conditions). Such data would feed back into clinical decision-making about the hierarchy of appropriate treatment options for a given patient. These data would also help shape the informed consent process and help establish the sorts of support and resources that should be made available to patients and their families, thus protecting the interests of future patient-subjects. Furthermore, the model can be tested and refined using both new indications for existing IBIDs and emerging IBIDs such as brain-interfacing prosthetic limbs and optogenetic technologies. While there is an ongoing debate within political science about the value of public deliberation as an input to policy development (e.g. Carpini et al., 2004), in the case of IBIDs, where patients and families are both members of the public and the most intimate stakeholders of the technology, their input into the process is critical.

Science moves rapidly. Patients, clinicians and the public benefit from research and policy that are responsive to the particular details of the technology under development, and are informed by the perspectives of those most affected by it – patients and their families. Clarifying what counts as risk and benefit in DBS will improve technology assessment and patient and human subjects protections. Developing an assessment model that is specifically tuned to the issues and concerns raised by IBIDs will further improve this process, ultimately benefiting future patients and patient-subjects.

Take-home points

Deep brain stimulation (DBS) is a novel technology with the power to modify personal identity and sense of self; it is likely to be the first in a series of implantable brain-interfacing devices (IBIDs) that has this capacity. Understanding patients' sense of self over time and following DBS is important not only for the informed consent process, but also for technology assessment and other questions of public policy.

Future directions

Research is required to assess the understanding, meaning and value of personal identity, and potential changes in personal identity, to patients and families. The collection of data relevant to changes in personal identity would enable the determination of the frequency and magnitude of risk of changes in personal identity posed by current and emerging IBIDs.

As indications for DBS broaden and new IBIDs are developed, potential risks to personal identity may need to be considered by patients, families, clinicians, scientists and society at large.

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