



Published in final edited form as:

AJOB Neurosci. 2017 ; 8(2): 73–75. doi:10.1080/21507740.2017.1320337.

Should we be concerned about preserving agency and personal identity in patients with Adaptive Deep Brain Stimulation systems?

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A considerable amount of theoretical neuroethics literature on deep brain stimulation (DBS) has focused on how DBS might impact agency and personal identity. The use of devices that stimulate specific brain regions and modify human outputs is fertile ground for philosophical examinations about the “self” including how these devices may transform our understanding of agency and personal identity. These are important and fascinating issues, particularly given the current development of next generation neural devices, such as adaptive DBS (aDBS) systems which are “smart” brain-computer interfaces that automatically adjust stimulation in response to an individual’s neural activity to regulate emotions, motor and behavioral outputs. Goering and colleagues (2017) argue that aDBS systems “have the potential to affect our identities, perhaps supporting us so that we can be whom we want to be, but perhaps also changing us in ways we wouldn’t want, even to the point of challenging our identity and/or agency.” We will argue that: 1) aDBS-related changes in agency and personal identity are not intrinsically negative outcomes and their impact will likely depend in large part on patients’ pre-aDBS pathological state; 2) the impact of aDBS on agency and personal identity needs to be empirically examined with aDBS patients and other stakeholders to generate and test well-informed hypotheses; and 3) when evaluating the development of aDBS systems as a medical intervention, the goal from an ethical perspective should not simply be to maximize the preservation of agency or personal identity, but to understand the risks and benefits (including positive and negative impacts on agency or personal identity), as well as the trade-offs of aDBS and to maximize its benefits and minimize harms.

CHANGES IN AGENCY OR PERSONAL IDENTITY ARE NOT INTRINSICALLY NEGATIVE OUTCOMES

Safe and effective aDBS systems would be a welcomed advance for the hundreds of thousands of individuals in the United States who suffer from treatment-resistant neuropsychiatric and movement disorders. Unlike open-loop DBS, aDBS can record neural activity or other symptom-related markers to automatically adjust stimulation in real time. Therefore, aDBS could potentially provide therapeutic stimulation only when necessary,

avoid overtreatment, and minimize programming trial and error and potential side effects. In addition, aDBS can lead to improved clinical responses over DBS because automatic adjustments avoid the delay between suboptimal symptom management and adjustment of stimulation in a clinical encounter. The automaticity of aDBS is promising from a therapeutic standpoint, but it exacerbates concerns that individuals may lose some degree of perceived or actual “control” or agency over their emotions and actions. Similarly, aDBS systems could alter personal identity by impacting the way individuals perceive, emotionally process, and respond to people, events, and other internal and environmental stimuli. However, changes in agency and identity are not intrinsically positive or negative outcomes of aDBS; their impact depends on multiple factors.

aDBS is currently in clinical trials for neuropsychiatric and movement disorders for which DBS has already shown some promise, such as obsessive-compulsive disorder (OCD; Goodman et al. 2010), depression, Tourette syndrome (Gunduz and Okun 2016), Parkinson disease (Starr 2013; de Hemptinne et al. 2015), and essential tremor (U.S. Department of Health and Human Services 2016a). All of these disorders can themselves affect agency or personal identity by altering patients’ neural function, leading, for example, to involuntary motor outputs, and changes in the way patients emotionally process and respond to stimuli. aDBS systems are an attempt to correct or prevent neural dysfunction that leads to pathological motor outputs, emotions, and behaviors. Generally, patients who are suitable candidates for aDBS suffer from intractable neuropsychiatric and movement disorders, therefore, their pre-aDBS pathological state is often highly disabling and more likely to lead to alterations in agency or personal identity than disorders whose symptoms are well-controlled with currently available clinical interventions. Whether post-aDBS effects on agency and identity are positive or negative outcomes will depend on whether patients and relatives experience post-aDBS changes in agency or identity as improvements compared to the intractable pre-aDBS pathological state. Importantly, even if post-aDBS changes in agency or identity are seen as overall net benefits in terms of symptom management and quality of life, there may be specific components of these changes that are considered intolerable or unacceptable by patients or relatives (Gilbert et al. 2017). Thus, it is essential to empirically examine these issues to develop a comprehensive understanding of how aDBS impacts agency and identity and to help develop ways of maximizing the clinical utility of aDBS.

NEED FOR EMPIRICAL EXAMINATION OF PATIENTS WITH ADBS AND OTHER KEY STAKEHOLDERS

Many, if not most, questions regarding the effect of aDBS on agency and identity, and how to maximize the clinical utility of these systems, are empirical questions. Goering and colleagues (2017) support several of their arguments regarding the potential impact of aDBS on agency and personal identity with theoretical work about the ethics of brain-computer interfaces and qualitative interviews with patients participating in open-loop DBS trials for depression and OCD (Klein et al. 2016). Although much theoretical literature has raised neuroethics issues related to DBS, there is a dearth of empirical neuroethics research on DBS and almost no research on aDBS systems (Lázaro-Muñoz 2017). Empirical neuroethics

research on aDBS is vital to assess the risks and benefits of these systems, including their impact on agency and identity.

aDBS is in an early stage of development, and groups such as the U.S. Brain Research through Advancing Innovative Neurotechnologies (BRAIN) Initiative, the National Institute of Mental Health (NIMH), National Institute of Neurological Disorders and Stroke (NINDS), and the Defense Advanced Research Projects Agency (DARPA), are making substantial investments to accelerate these technologies. (U.S. Department of Health and Human Services 2016a). Therefore, if we want to help guide the responsible development and translation of aDBS systems, this is the time when we must begin to empirically examine these aDBS neuroethics issues in collaboration with the researchers developing these neurotechnologies. The BRAIN Initiative has recognized the importance and need for collaborative empirical neuroethics research in this area (BRAIN Working Group 2014; U.S. Department of Health and Human Services 2016b).

aDBS empirical neuroethics research will help us begin generating and testing hypotheses about the agency and identity-related risks and benefits of aDBS. For example, to assess the risks and benefits of aDBS, we need to answer the following questions: 1) how often are concerns or changes in agency and personal identity reported by aDBS patients and relatives; 2) how are these perceived or actual changes in agency and identity manifested and experienced by aDBS patients and other key stakeholders; 3) what is the magnitude of these changes; 4) do aDBS patients or relatives express regret about undergoing aDBS because of its impact on agency and identity; 5) how could we potentially minimize the likelihood of experiencing unwanted changes in agency and identity; 6) what interventions may help manage these changes for those who experience them as unwanted effects of aDBS: psychotherapy, adjustments in stimulation, aDBS patient support groups? Empirical neuroethics research in which aDBS patients, relatives, and other key stakeholders are interviewed to understand their experiences and perspectives before and after aDBS is the first necessary step. This will allow the field to understand the actual manifestation of these changes in aDBS patients and to generate hypotheses about the frequency and magnitude of these changes and about what may be done to manage them. Once well-informed hypotheses are generated they can be tested with large samples of aDBS patients to reach well-informed conclusions that can help guide the responsible development and translation of aDBS systems.

PRESERVATION OF AGENCY AND PERSONAL IDENTITY AS A GOAL

Finally, since intractable pre-aDBS pathology can alter agency and personal identity, probably as much or perhaps even more than aDBS, we believe that when it comes to the development of aDBS systems, the goal from an ethical perspective should not be to maximize the preservation of agency or personal identity experienced in the pre-aDBS pathological state. The goal should be to examine the risks, benefits, and trade-offs of aDBS, how observed changes in identity and/or agency are perceived by patients and families in light of intractable psychiatric and movement disorders, and identify what can be done to minimize harms for those who experience these (or some components of these changes) as unwanted effects. This aDBS neuroethics research will be beneficial in at least three critical

ways. First, it will help determine the safety and, to some degree, the effectiveness of aDBS for certain psychiatric, movement or other disorders. Second, clinicians will be able to provide accurate information regarding the potential effect of aDBS on agency and personal identity to help patients make an informed decision regarding whether to undergo aDBS surgery. Third, understanding these potential effects of aDBS can help inform the development of strategies to minimize potential harms and maximize clinical utility so that those who could benefit from these technologies are more willing to access them and hopefully enjoy healthier lives.

Acknowledgments

Research for this article was funded by the National Institutes of Health (NIH) Grants K99HG008689 (Lázaro-Muñoz G) and 1UH3NS100549-01 (Goodman W). The views expressed are those of the authors alone, and do not necessarily reflect views of NIH.

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