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# The Development of Self-Trust in DBS Patients

Ashley E. Walton

Dartmouth College

Schönau et al. (2021) provides essential concepts and methodological tools for examining the complex interactions that emerge between neurotechnology and an individual's agency. The authors describe the agency dimension of trust as an individual's trust in themselves to make use of feedback provided by neurological interventions in order to effectively evaluate their own experience and choose how to act within their environments. Their discussion is restricted to issues of sensory feedback for those using brain computer interfaces (BCIs). However, this also presents an opportunity to consider the emotional effects that can result from deep brain stimulation (DBS) as a type of feedback for which individuals must develop self-trust regarding their ability to reflect and act upon these experiences. Building upon the authors' work, I discuss the relational aspects of self-trust for DBS patients, focusing on the adjustment of stimulation parameters and the future potential of autonomous neurostimulation.

Consider their case study of Cora, an individual using DBS for major depressive disorder. For Cora, the relevant feedback is her feelings (or lack thereof) in response to her friend's funeral, where she is left wondering whether her emotional reaction is attributable to her DBS or to aspects of her relationship with her friend. In the same way that BCI users must learn to trust their understanding and use of sensory feedback, DBS users must learn to trust themselves in the reflection and interpretation of their emotional responses. The process of interpreting and negotiating changes to emotional experiences is of particular importance to DBS, as there is often a need and opportunity to adjust and "fine-tune" the stimulation parameters to fit the needs of individual patients.

Thus, patients must identify what experiences represent desired control of their symptoms versus undesired side effects. Due to the wide range of variability with regards to disease experience, effects of DBS, and how these effects impact the abilities meaningful to individual patients, it is essential for patients to contribute actively to the process of identifying the stimulation effects that best work for them– and to trust themselves in doing so.

Developing and practicing this trust occurs in the context of interactions with caregivers and close others (Brown 2020). While Schönau et al.'s case study describes Cora as alone in reflecting and interpreting the meaning of her emotional experience, there are often friends or family members that play an essential role in how we understand and interpret our emotional reactions, and thus support our ability to trust ourselves in acting upon these experiences in ways that help us meet desired ends. For example, Cora may describe what she is experiencing at the funeral to a close friend that then attests to the significance of the deceased to Cora, providing information that helps Cora interpret what she is feeling. She then might try to express grief in some other form, as a private tribute or donation to the deceased's family. While these situations are not ideal, Cora may decide that she trusts herself to be able to manage them sufficiently, and that the overall effects of DBS in controlling her depressive moods is an acceptable trade off. Although caregiver relationships are often characterized by support, in some instances they may introduce tension and disagreement in a patients' experience and interpretation of DBS effects (Klein et al. 2016). As emotional experiences can be deeply situated within social contexts, it will be essential to

CONTACT Ashley E. Walton ✉ ashley.walton@dartmouth.edu 🖳 Department of Philosophy, Dartmouth College, Hanover, MD 03755-3529, USA

understand the role of close others when aiming to support patients' development of self-trust, as well as the impact of DBS on agency more broadly (Muñoz et al. 2020; Brown 2020; Klein et al. 2016; Goering et al. 2017; Mackenzie 2014).

Crucial touchpoints in the practice of self-trust for DBS patients are post-surgical appointments in which they work with their clinician to adjust stimulation settings in response to observed changes in behavior and symptoms. This implicates both caregivers and clinicians, as well as the interactions between the two, in the emergence of patients' trust in their ability to understand and communicate effects of stimulation. Clinicians facilitate this self-trust by interacting with patients as capable arbiters of how their experiences of DBS can be best aligned with what is important and meaningful to them (Klein 2015). Thus, closely related to the practice of self-trust is patients' confidence and skills in self-reflection, and the ability to use these observations to communicate desired changes (Brown, 2020; Mackenzie 2014). In some instances, a patient may not be able to use DBS feedback to this end because the effects of stimulation leave them unaware or unable to judge whether their behaviors as harmful (Klein 2015). In these instances, intervention by a clinician can identify stimulation parameters that restore patient's agency across multiple dimensions, as a breakdown in the ability to effectively evaluate one's experience is simultaneously detrimental to the dimensions of self-trust, responsibility and authenticity outlined by Schönau et al. (2021). Analytical approaches for describing the complex interconnections and exchanges across the multiple dimensions of agency will help guide systematic approaches to best supporting patients as these issues emerge during the months after implantation (Roskies 2015).

Future developments in adaptive deep brain stimulation aim to improve stimulation delivery to eliminate the need for iteratively "fine-tuning" parameters in response to patient experience. Improved electrode placement will better target neurological function, and algorithms will be developed for automatically adjusting stimulation over time in order to optimize symptom control while minimizing side effects. Importantly, a patient's ability to trust their experience and provide feedback regarding the effects of different stimulation parameters will be an essential contribution to the development of these algorithms. It is also possible that this process will never be entirely eliminated, as some aspects of stimulation effects may always need to be informed by individual patient needs and preferences (Klein 2020; Muñoz et al. 2020). For example, if patient reports of "I don't feel like myself" are to be addressed as a clinical symptom (Klein 2015), it is doubtful a universal set of algorithms will be able to account for the range of stimulation effects and adjustment options potentially relevant to an individual "feeling like themselves" within the various environmental and social contexts of their everyday lives (de Haan et al. 2013; Baylis 2013). Thus, patient self-trust will contribute not only to the initial stimulation settings but will also be an indispensable component of determining the continued success of neurostimulation over time.

Advances in technology and neuroscientific knowledge hope to bring a clearer distinction between instances where stimulation should be autonomously adapted independently of patient input versus stimulation in which they should be kept "in the loop" in order to assess and potentially alter its effects (Muñoz et al. 2020; Klein et al. 2016; Goering 2015). Maybe Cora would prefer to be able to "self-modulate" her DBS in order to best attune the effects of stimulation to the demands of her everyday life, in this case preferring to have the capacity to engage in a particular kind of emotional expression at a funeral. Post-operative stimulation adjustments may define the initial space of a patient's agency map, where thereafter patients are able to choose when to adjust certain stimulation settings to their own ends, perhaps in some cases prioritizing one agency dimension over another (Klein 2015). Further exploring the relationships between the dimensions proposed by Schönau et al. (2021) will prove essential to understanding how technology can develop alongside patients' recognition and communication of the diverse ways that neurointerventions support and redefine their agency.

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# Responsibility, Authenticity and the Self in the Case of Symbiotic Technology

Giulio Mecacci [iD] and W.F.G (Pim) Haselager

Donders Institute for Brain Cognition and Behaviour, Radboud University

The target article (Schönau et al. 2021) recognizes four key ethical dimensions, or values, that are affected by neurotechnology, and proposes that the notion of agency can provide a unifying conceptual framework to map and navigate them. We praise the proposal and the range of insights that it enables. In the following, we aim to show two things. First, that one of the ethical dimensions, "responsibility," should be further refined to make sense of the cases presented by the authors. Second, that such refinement can use conceptual components that are already in the framework, i.e. the dimension of "authenticity," potentially indicating how the four ethical dimensions might be further intertwined with each other. This, we believe, opens up avenues for further research and development of the proposed framework.

The authors of the target article claim that "the dimension of responsibility is linked to the agential competency of exercising control." They propose to "understand the issue of responsibility ascription primarily as a problem of intentional control." "The more an agent," they continue, "is able to perform intentional action within [a BCI system's] control-loop, the more responsible he is for the outcome of that action. Conversely, if a malfunction results in the agent falling out of his control loop, responsibility

CONTACT Giulio Mecacci ✉ g.mecacci@donders.ru.nl 🖃 Artificial Intelligence Department, Donders Institute for Brain Cognition and Behaviour, Radboud University, Nijmegen, The Netherlands.