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Controlling our brains – a case study on the implications of brain-computer interface-triggered deep brain stimulation for essential tremor

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ABSTRACT

Deep brain stimulators (DBS) are a neurotechnological means of treating a variety of movement disorders, including essential tremor (ET). Current stimulation systems apply an electrical current to targets in the brain at a constant rate for as long as they are implanted and activated – treating symptoms but causing uncomfortable side-effects and inefficient power usage. Some users feel estranged or isolated for various reasons. Next-generation DBS systems could use the patient's self-modulated neural signals to trigger stimulation. These brain-computer interface-triggered DBS (BCI-DBS) systems would give the user the ability to moderate side-effects and reduce battery power consumption. It's not yet clear, however, whether neural control will alleviate or exacerbate psychosocial problems. To explore these concerns, we conducted interviews with an ET patient using an experimental BCI-DBS platform. Our interviews offer preliminary insights about what problems ET patients may face while using BCI-DBS.

1. Introduction

Deep brain stimulation (DBS) is used as means of treating a variety of movement disorders, including essential tremor (ET).[1] Although pharmaceuticals are an effective treatment for mild-to-moderate ET symptoms, they are often ineffective in moderate-to-severe cases.[2] Recently, DBS has become a recommended intervention.[3,4] Most DBS systems are 'open-loop': they apply a steady pre-set stimulation pattern for as long as the device is implanted and activated (or until next changed by the clinician).

Open-loop DBS (OL-DBS), however, has its pitfalls. Most OL-DBS systems use a battery contained in the stimulator, which is surgically implanted under the clavicle and connected to the stimulation electrodes via implanted wires. Once the battery runs down – between two and five years [5] – the battery unit must be replaced surgically. ET patients using DBS can also experience side-effects such as paresthesias in the limbs, weak or slurred speech, and problems controlling behavioral impulses.[6–8] The clinician can sometimes manage these symptoms by adjusting OL-DBS stimulation parameters, but some patients have persistent side-effects.[6] In addition, some patients report psychosocial difficulties after implantation – feelings of self-estrangement, an altered self-image, a lack of motivation, and alienation from others. These are possibly difficulties 'of reintegrating into [their] socio-familial and professional environment'.[9,10] The causes and implications of these maladaptations are the subject of on-going debate.[11–14]

'Closed-loop' (CL-DBS) systems offer a possible solution to many of the problems with open-loop systems. Where an OL-DBS system applies stimulation constantly, a CL-DBS system could trigger stimulation only when the patient needs it [15] – such a system could detect tremor using signals from wearable sensors [15] or from neural signals.[16] By applying stimulation less often, power is conserved and battery life is extended.

To limit unwanted side-effects, one solution is to offer the user control over their stimulation. Current OL-DBS systems, however, are adjusted using hand-held, 'patient programmer' devices – but if the user is dealing with severe-enough tremor, they may find it difficult to use a hand-held device. Another alternative is to give the user the ability to trigger their DBS by modulating their neural activity. One such system would use implanted electrodes – e.g. electrocorticography (ECoG) electrodes

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implanted over the motor cortex – to measure either overt or imagined hand movements. The system would use on-board computation to recognize user commands and determine appropriate stimulation adjustments. Such a brain-computer interface-triggered DBS (BCI-DBS) system would give the user voluntary control of the trade-off between tremor symptoms and unwanted side-effects.

BCI-DBS systems may, however, present the user with another set of problems. Would the user welcome this level and mode of control? Would the user need to make (perhaps unforeseen) choices they would rather not make? Would these systems cause changes to the user's interpersonal life? To explore these questions, we conducted a series of interviews with a person with ET using an experimental CL-DBS / BCI-DBS platform. Here we use the results from these interviews as a preliminary look at difficulties that may arise when the user has control over their stimulation. While new modes of control may address some of the issues users have in making trade-offs, the user of such a device may be faced with new trade-offs entirely. BCI-DBS users, we argue, will possibly face challenges to their ability to negotiate trade-offs competently or in ways that satisfy them.

2. Background: narrative identity, autonomy competence, and neural control

We noted earlier that people with Parkinson's disease have reported negative psychosocial effects while using DBS: feeling 'like [a] robot', feeling 'forced to live like a prisoner in an alien body that's out of control', or wanting 'to be recognized as sick'.[9,10] Some argue that these reactions are evidence that DBS systems (along with other neurotechnological medical devices) can threaten (or strengthen) their users' identities – or rather, DBS can render their users either more or less able to be their authentic selves. Felicitas Kraemer, for one, explains these effects through an *authenticity view* of self-identity. She argues that 'when evaluating the ethical […] implications of behavior changes that result from DBS, the subjective state of felt-authenticity and felt-alienation should be taken into consideration' [11] so that we can better attend to how each patient's experience using DBS may be a process of 'recognizing, exploring, and enacting what they regarded as their "true selves"'. [12] If, for example, DBS enables a person with ET to eat in public without feeling embarrassed, that user might feel more like themselves again and less alienated from their own bodies. If, however, the user has trouble speaking while receiving stimulation, they may feel even more alienated from their bodies, their dinner partners, and so on.

Others argue that it is misleading to say that people have an 'authentic self' that they can conform to or fall out of alignment with. Along these lines, Françoise Baylis argues that a person's identity is *dynamic*, *narrative*, and *relational*: who we are changes with our lived experiences, the self-narratives we take as constitutive of our identities, and the constraints placed on our self-narratives through our interpersonal relationships. The relational component is particularly important to Baylis's view. Built into our relationship with others there is a tension between how we describe ourselves and how others describe us: we cannot describe ourselves any way we want, and others cannot describe us however they want. There is, in Baylis's terms, an 'equilibrium constraint' on our self-narratives. 'Relational identity', then, 'is a dialectical process aimed at achieving equilibrium – some kind of temporary and temporizing balance between self-ascription and ascription by others'.[13] Baylis concludes, 'the notion of an authentic self "given by nature and unchanged by time" [is] outdated, [and] changes in these domains do not represent a threat to personal identity, but rather are constitutive of personal identity'.[13] That is, when DBS causes a change that makes its user feel out of sorts, it is not just because DBS has somehow made it more difficult for the user to feel or act authentically. After all, DBS users can (and often do) form an identity-constitutive self-narrative about their lives with DBS, and their loved ones can (and often do) corroborate or contribute to those narratives. When a DBS user feels out of sorts, it may just be that they feel dissatisfied with the self-narratives available to them, unsatisfied with the narratives their friends and family make on their behalf, or uncomfortable 'performing' any of these self-narratives. DBS, in this sense, is not unlike other technologies or situations (e.g. cell phones, new jobs, etc.) that impact our senses of self and the stories we tell about ourselves.

Catriona Mackenzie and Mary Walker underscore Baylis's argument against the authenticity-view and extend it. They argue that 'the appeal to authenticity is redundant and blurs the distinction between narrative identity and autonomy' [14]; not only does the authenticity view obscure details about how DBS users form, reform, and perform their identities, authenticity-talk obscures the details of how DBS can impair or bolster the user's ability to act autonomously. To this end, Mackenzie and Walker adopt Diana Meyers's process view of autonomy, where autonomy is a set of competencies that are required for 'self-discovery, self-direction, and self-definition'.[17] In order to be autonomous, Meyers argues, '[we] must be able to pose and answer the question "What do I really want, need, care about, value, etcetera?"; [we] must be able to act on the answer; and we must be able to correct [ourselves] when [we] get the answer wrong'.[18] In better cases, DBS can make a positive impact on these autonomy competencies: where a person with ET would have

to make decisions around their symptoms, DBS may give them the ability to act on desires, unhindered by the effects of ET. In worse cases, however, DBS's side-effects can make it difficult for the user to control their own impulses.[8,19] On their view, 'the salient issue […] is not whether such interventions threaten identity, but whether they impair autonomy competence'.[14]

If, however, Mackenzie and Walker are correct that the authenticity view 'blurs the distinction between narrative identity and autonomy', BCI-triggered DBS may blur that line even more. BCI-DBS (or even manually adjusted OL-DBS) gives the user the ability to modulate their neurological activity in a way they did not have before. This new ability may play a key role in the user's identity-constitutive narratives as well as their everyday decision-making – and so each user will need to decide how best to understand, determine, and describe their DBS's role in their life. Different modes of controlling DBS, however, add another layer of difficulty in understanding ourselves and explaining ourselves to others. We can think of closed-loop or BCI control, then, as an added test or challenge for the user's autonomy competency. The salient issue, then, is not only whether DBS *undermines* or *fosters* autonomy competence, but also how it *complicates* or *tests* autonomy competence by creating new challenges for users, their friends, and their families. Below, we'll look at these issues through the experiences of a person learning to live with ET, DBS, and experimental forms of controlling their DBS.

3. A case study

We conducted a series of interviews with an ET patient as he tested an experimental DBS and BCI platform. We kept these interviews open-ended and semi-structured – tailoring the questions to each research visit – in order to better capture the patient's honest (and changing) feedback. These interviews were approved by the University of Washington's Institutional Review Board (IRB). Before participating in these interviews, our team approached the patient – we'll call him 'George' – and obtained his consent in accordance with IRB's regulations for informed consent. All interview transcripts were recorded and transcribed.

George is a 58-year-old man who has been dealing with action tremor in his right arm and right leg for approximately four years. His tremor became more severe after two years, and this impacted the activities of his daily life – in particular, he found it difficult to eat, drink, or write. Tremor also impacted George's interpersonal life. He was laid off from his previous job – his employer thought he was unfit for clerical tasks. George tried several pharmaceutical treatments with little to no success: propranolol had no significant benefit, and primidone caused unacceptable side-effects.

George's surgeon (Dr. Andrew Ko) implanted him with an Activa PC+S neurostimulator unit, stimulation electrodes in the ventral intermediate nucleus of his thalamus, and a strip of four spinal-stimulation electrodes over the right-hand side of his motor (M1) and somatosensory (S1) cortices. The Activa PC+S is able to both sense data from and stimulate using the implanted electrodes. Stimulation and sensing control functions were performed using Medtronic's Nexus-D communication device. George volunteered for a study to test this new system in several modes. First, the DBS system was connected to both an EMG sensing system and a smartwatch that detects tremor and triggers stimulation (a wearable CL-DBS system). Second, signals were captured from the electrodes above George's motor cortex as he performed overt and imagined arm and hand movements, and these signals were used to control a cursor for a BCI control task (for more detail, see [20]). As of this writing, we have met with George five times over a period of 6 months post-op.

3.1. Getting familiar with the implant

At his first research visit, George explained that it was difficult get used to both how his implants feel, and the possibility that others might notice it. A month after surgery, George explained, 'I feel like I've got a conduit going down the back of my neck. I'm always rubbing on it'. He recounted feeling self-conscious around other people – as if they could see the implanted leads through his skin. When asked if it truly would bother him if people could see them, he said, 'I would just deal with it. I think it's more of a curiosity … of what [other people can see] and where, because I don't know'. He wanted to know what people could see, what they couldn't see, and what he could do about it. When asked if there is ever a moment when he forgets that he has a neural implant, George replied simply: 'No.'

George also suggested that it is difficult to discern stimulation side-effects from ET symptoms or other health problems. Several months after surgery, George had an intense headache immediately after turning off his stimulator, and he insisted that turning off the stimulator caused the headache. A month later, he worried that the opposite was true: that his headaches were a side-effect of stimulation. George also noticed muscle spasms in his right forearm. He wondered if stimulation caused these spasms, or if they were related to ET in general. George also noted that his wife thought stimulation was causing him to walk in a stiff-legged way – as if he were 'goose-stepping'. He insisted, however, that he wasn't aware of or worried about any change in his ability to walk.

Although the stimulator is intended to help him to act in an autonomous way, George also faces difficult

questions about how best to use the device as he works to incorporate it into his self-narrative. As such, the above-mentioned uncertainties may make it difficult for George to determine how best to use his stimulator. Should he turn it on or off when he has a headache? Should he turn it on when someone insists that he's walking differently? How will he know that he's made the right choices if he cannot disambiguate the side-effects of stimulation from his other medical problems?

3.2. Saving power

After several conversations across several research visits, George expressed an interest in improving his neurostimulator's power efficiency. First, he wondered if a system that conserves battery power could be built with a smaller battery and, thus, a thinner profile. Second, George explained that he wanted to conserve power in order to extend his stimulator's battery life – thereby avoiding the follow-up surgery necessary to replace the stimulator unit. He reported that he kept his stimulator turned deactivated '95% of the time', and he only activated it when he wanted to eat or write without tremor symptoms. 'Half the time,' he explained, 'I don't worry about it.' Finally, he voiced worries about being able to afford battery replacements once he and his wife reach retirement. George's remarks suggest that, for him, the prospect of saving power (and thus avoiding the cost and effort required to replace the battery) is worth experiencing additional tremor. CL-DBS would, perhaps, make it possible for George to conserve battery power without making adjustments himself. The closed-loop system's algorithm, however, would need to conserve enough power to achieve George's goals.

The ability to save power, however, may come with additional normative consequences. Perhaps a user will want conserve power because they cannot afford a second round of surgery or a replacement neurostimulator unit. This user's socioeconomic situation would factor into the trade-offs they make between dealing with stimulation side-effects and dealing with ET symptoms. Suppose, further, that the user's insurance provider sets limits on how often they will pay for replacement neurostimulator units.[21] The user may *want* to use their stimulator, but feel guilty or worried about the potential financial losses when they do. As a result, BCI-DBS users may fall into non-adherence to treatment similar to non-adherence to prescribed medications.[22]

Here we can see that the trade-offs required for open-loop use of the stimulator (e.g. needing battery changes, additional surgeries, etc.) are not fully acceptable to George and so he negotiates his own way of using the system. Getting the benefits of a well-functioning DBS system, then, requires more than a reliable device. As we look ahead to CL-DBS and BCI-DBS, we need to understand the non-ideal contexts in which individuals will use such devices, the associated constraints on effectiveness, and the individual user's outlook on these contexts.

3.3. BCI control

In order to modulate stimulation parameters using neural commands, the user must first be able to modulate his cortical activity. To this end, George was asked to learn to perform a series of BCI tasks. In each of these tasks, he exerted one-dimensional control over a cursor by imagining movements or making overt movements with his right hand and thereby modulating beta-band power. An imagined or overt movement caused the cursor to move in one direction, and a period of rest would move the cursor in the opposite direction. For each trial of these tasks, a goal marker would appear on the screen, and George's goal was to move the cursor to hit the target. He found these tasks difficult at first. When asked how difficult it was to move the cursor after his first few trials, he explained, 'On a one-to-ten […] it's probably about an 8' and 'I was breaking out in a sweat trying to do it!' When asked if it's harder than typing with tremor symptoms, he insisted that BCI control was more difficult: 'When I was [typing], I could always backspace and just get frustrated. The tremor stuff, that's how that was – it was more frustration than, you know, [this game] kickin' my butt.' These tasks became less taxing over time, but there were several times when he insisted that he wasn't looking forward to BCI control tasks.

When asked if he would find more visual feedback helpful – e.g. an image of a needle jumping that corresponds to changes in beta-band power – he insisted that it wouldn't be. 'I wouldn't understand those,' he explained, 'I'm kind of simple-minded.' When asked if he had thought of strategies he could use to perform better during BCI tasks, he said, '[I was] just trying to figure out how I can relax and get it to do it, but … I don't see me relaxing'. George insisted that he is the sort of person whose thoughts are constantly racing. 'My mind is constantly going faster,' he explained, 'I'm always thinking what to do, how to change things.' He must, however, stop imagining movement in order to manipulate the cursor in the BCI game or to, inevitably, control his stimulation parameters.

George's concerns about his ability to perform BCI-control tasks seemed closely tied with his self-narratives. He is by his own account 'simple' and 'easy-going'. These beliefs about himself may either help or harm his ability to perform BCI control tasks as he learns what he's capable of, decides how he wants to make use of those capacities, and learns from his mistakes. This pairs well with recent arguments that social factors impact BCI performance more than previously anticipated, and the argument that

BCI-training protocols could be greatly improved by matching the psychosocial circumstances of BCI learners.[23–27] It is likely that George's preferred mode of BCI control will be the one that best accommodates his desires (to save battery) and his self-descriptions (that he is 'easy-going' and that his 'mind is constantly going faster.').

4. Conclusion

The above case study gives us a small preview of the possible worries ET patients may have about BCI-triggered DBS. One case study cannot generate an exhaustive list of concerns (if it is even possible to generate such a list) or to identify one concern as more urgent than others (if it is even useful to do so). We can, however, see that while BCI-DBS stands to give ET patients a powerful form of control over their neurostimulators, this control may come with additional challenges particular to the technology. BCI-DBS users will need to determine how to use their neurostimulator in a way that they can live with. As such, clinicians will need to pay attention to what their patients want from BCI control, how they incorporate BCI-DBS into their everyday lives, and how each patient's values could hinder or help them throughout the process. Future engineering research on BCI-DBS should collect a larger sample of patient perspectives on the purpose, design, and real-world use of BCI-control. These patient perspectives, if they receive uptake, should help engineers and clinicians navigate the trade-offs between various modes of user control.

Disclosure statement

No potential conflict of interest was reported by the authors.

References

[1] Melamed E, Ziv I, Djaldetti R. Management of motor complications in advanced Parkinson's disease. Mov Disord. Wiley Subscription Services, Inc., A Wiley Company. 2007 Jan 1;22:S379–84.

[2] Gironell A, Kulisevsky J. Review: diagnosis and management of essential tremor and dystonic tremor. Ther Adv Neurol Disord. SAGE Publications. 2009 Jul 1;2:215–222.

[3] Schuepbach WMM, Rau J, Knudsen K, et al. Neurostimulation for Parkinson's disease with early motor complications. Massachusetts Med Soc. 2013 Feb 13. 387:610–22.

[4] Charles PD, Dolhun RM, Gill CE, et al. Deep brain stimulation in early Parkinson's disease: enrollment experience from a pilot trial. Parkinsonism Relat Disord. 2012 Mar;18:268–273.

[5] Ondo WG, Meilak C, Vuong KD. Predictors of battery life for the Activa® Soletra 7426 Neurostimulator. Parkinsonism Relat Disord. 2007 May;13:240–242.

[6] Kuncel AM, Cooper SE, Wolgamuth BR, et al. Clinical response to varying the stimulus parameters in deep brain stimulation for essential tremor. Mov Disord. 2006;21:1920–1928.

[7] Hariz MI, Rehncrona S, Quinn NP, et al. Multicenter study on deep brain stimulation in Parkinson's disease: an independent assessment of reported adverse events at 4 years. Mov Disord. 2008 Feb 15;23:416–421.

[8] Smeding HMM, Goudriaan AE, Foncke EMJ, et al. Pathological gambling after bilateral subthalamic nucleus stimulation in Parkinson disease. J Neurol Neurosurg Psychiatry. BMJ Publishing Group Ltd; 2007 May 1;78:517–519.

[9] Agid Y, Schüpbach M, Gargiulo M, et al. Neurosurgery in Parkinson's disease: the doctor is happy, the patient less so? J Neural Transm. 2006;70:409–14.

[10] Schüpbach M, Gargiulo M, Welter ML, et al. Neurosurgery in Parkinson disease A distressed mind in a repaired body? Neurology. 2006;66:1811–1816.

[11] Kraemer F. Authenticity anyone? the enhancement of emotions via neuro-psychopharmacology. Neuroethics. Springer Netherlands. 2011;4:51–64.

[12] Kraemer F. Me, myself and my brain implant: deep brain stimulation raises questions of personal authenticity and alienation. Neuroethics. 2011 May 12;6:483–497.

[13] Baylis F. 'I Am Who I Am': on the perceived threats to personal identity from deep brain stimulation. Neuroethics. 2011 Sep 14;6:513–526.

[14] Mackenzie C, Walker M. Neurotechnologies, personal identity, and the ethics of authenticity. In: Clausen J, Levy N, editors. Handbook of neuroethics. Dordrecht: Springer Netherlands; 2014. p. 373–392.

[15] Hebb AO, Zhang JJ, Mahoor MH, et al. Creating the feedback loop. Neurosurg Clin N Am. 2014 Jan;25:187–204.

[16] Herron J, Denison T, Chizeck HJ. Closed-loop DBS with movement intention. In: Proceedings of the 7th International IEEE/EMBS Conference on Neural Engineering; 2015 Apr 22-24; Montpellier, France; p. 844–7.

[17] Mackenzie C, Stoljar N. Relational autonomy. Stoljar N, editor. Oxford: Oxford University Press; 2000. p. 1.

[18] Meyers DT. Self, society, and personal choice. New York (NY): Columbia University Press; 1991. p. 1.

[19] Leentjens A, Visser-Vandewalle V, Temel Y. Manipuleerbare wilsbekwaamheid: een ethisch probleem bij elektrostimulatie van de nucleus subthalamicus voor ernstige ziekte van Parkinson [Manipulable mental competence: an ethical problem with electrical stimulation of the subthalamic nucleus for severe Parkinson's disease]. Nederlands Tijdschrift. 2004. Dutch.

[20] Thompson MC, Herron J. Demonstration of a chronic brain-computer interface using a deep brain stimulator. Poster presented at: Sixth International BCI Meeting; 2016 May 30-June 3; Pacific Grove, CA.

[21] Rossi PJ, Okun M, Giordano J. Translational imperatives in deep brain stimulation research: addressing neuroethical issues of consequences and continuity of clinical care. UABN. 2014;5:46–8.

[22] Louis ED. Medication non-adherence in essential tremor. Parkinsonism Relat Disord. 2015 Feb;21:138–141.

[23] Lotte F, Larrue F, Mühl C. Flaws in current human training protocols for spontaneous brain-computer interfaces: lessons learned from instructional design. Frontiers in Human Neuroscience. 2013 Sep 17;7:1–11.

[24] Lotte F. On the need for alternative feedback training approaches for BCI. Berlin Brain-Computer Interface Workshop. Paper presented at: Berlin Brain-Computer Interface Workshop; 2012 Sep 17–19; Berlin, Germany.

[25] Lotte F, Jeunet C. Towards improved BCI based on human learning principles. Paper presented at: 3rd International Winter Conference on Brain-Computer Interface; 2015 Jan 12–15. South Korea.

[26] Grübler G, Al-Khodairy A, Leeb R, et al. Psychosocial and ethical aspects in non-invasive EEG-based BCI research – a survey among BCI users and BCI professionals. Neuroethics. 2013 Feb 3;7:29–41.

[27] Sexton CA. The overlooked potential for social factors to improve effectiveness of brain-computer interfaces. Front Syst Neurosci. 2015 May 6;9:693–695.