Building Intricate Partnerships with Neurotechnology: Deep Brain Stimulation and Relational Agency

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Abstract: Deep Brain Stimulation (DBS) is an FDA-approved treatment for symptoms of motor disorders—with experimental use for psychiatric disorders. DBS, however, causes a variety of side effects. Moral philosophers question DBS's influence on users' experiences of authenticity, identity, and/or autonomy. These characterizations of DBS, however, may not make sense of how DBS complicates, rather than simply impedes or bolsters, users' abilities to exercise agency. Empirical work exploring DBS users' lived-experiences and feminist accounts of relational autonomy demonstrate that the issues users face are better characterized in terms of the user's relationship to their stimulator, that is, in terms of "relational agency."

1. Introduction

Deep Brain Stimulation (DBS) is an FDA-approved treatment for the symptoms of Parkinson's disease (PD), essential tremor (ET), dystonia, and epilepsy—with experimental use for mood disorders. DBS systems consist of a signal generator, typically implanted in the user's chest, that sends impulses to electrodes implanted in select areas of the user's brain. These signals change the activity of areas of the brain associated with unwanted symptoms. Several research groups have begun trials to use DBS as a treatment for psychiatric disorders (e.g., major depression [Mayberg et al. 2005; Mayberg 2008; Mayberg et al.2016; Widge et al. 2015] and obsessive-compulsive disorder [Alonso et al. 2015]). DBS, however, comes with a number of physiological and psychological side effects. People using DBS to manage motor disorders, for example, may experience paresthesias (tingling sensations) in their limbs, weak or slurred speech, or feelings of euphoria (Kuncel et al. 2006; Smeding et al. 2007; Hariz et al. 2008).

Some users also report more severe neuropsychiatric problems postsurgery (Voon et al. 2006). A small subset of people with PD develop impulsivity and risk-taking behaviors (e.g., gambling) as a side effect of stimulation of the sub-thalamic nucleus (Smeding et al. 2007). Changes like these can result in lifestyle and social difficulties: an altered self-image, feelings of self-estrangement, and a lack of motivation (Schüpbach et al. 2006; Agid et al. 2006; Kraemer 2011b). In one study, people using DBS for PD reported a variety of self-impressions, including that DBS makes them "feel like a 'Robocop'" or like they're "forced to live in a body that's out of control" (Agid et al. 2006, 412). Others noticed changes in their interpersonal relationships. One woman acting as a caregiver for her husband with PD explains, "since the operation, [my husband] wants to live like a young man . . . I prefer him as he was before, always nice and quiet" (412). The nature of and appropriate response to these so-termed "psychosocial" changes is a matter of ongoing debate (Mecacci and Haselager 2014; Haan et al. 2017), but a recent pilot study suggests that concurrent education sessions may help reduce some of the anxiety and depression in some patients (Dos Santos et al. 2017).

Some commentators frame these psychosocial changes in terms of DBS's effects on selfhood: DBS may make the user feel inauthentic (Kraemer 2011b, 2013), shift important features of their identity (Glannon 2009), or diminish their autonomy (Mackenzie and Walker 2015). These views characterize DBS as an external force that can confound or bolster these features of selfhood. Such views may, however, have difficulty parsing cases where users have trouble distinguishing between their own behaviors and those behaviors influenced or instigated by stimulation. For example, some people using DBS for depression and obsessive-compulsive disorder have reported problems determining if their actions are "their own" or if they are the result of stimulation's side effects. In moments like these, I maintain, DBS users experience confusion with respect to their sense and exercise of agency. In fact, some DBS users are actually put in a position where they develop intricate partnerships with DBS in order to exercise agency.

That is not to say we should not characterize these negative outcomes as cases of felt-inauthenticity, identity change, or autonomy encroachment—these modes of explaining DBS users' experiences are all useful in certain contexts, and users' experiences vary widely enough that it is possible that they benefit from multiple modes of description at once. My view, however, is that we are better able to anticipate and address the issues DBS users face, such as the afore-mentioned feelings of ambiguity, when we home in on the intricacies of the users' relationships to their stimulators and the agency they share as a result. The ability to make sense of these partnerships will be vital as DBS becomes a more common treatment for a wider variety of conditions and as advanced, artificially-intelligent DBS systems become more commonplace.

I begin by considering the aforementioned three views of how DBS changes selfhood and identifying the potential gaps in them. I propose that each of these views fall short of capturing users' experiences of struggling against or along-side their neurostimulators. These experiences, I maintain, are the product of a

relationship some users form with their DBS systems. I present two cases where DBS users run into difficulties in these relationships—the aforementioned agential ambiguities people navigate when they use DBS for psychiatric disorders—and the tradeoffs people negotiate when they use DBS for motor disorders. I suggest that we can make sense of these cases by making use of a notion of "relational agency"—according to which DBS users' exercises of agency may be supported, encumbered, and otherwise "intertwined with" their DBS systems (Goering et al. 2017, 67). Finally, I propose the concept of an "agential competence"—building on Diana Meyers's notion of autonomy competences—as a first attempt to codify strategies DBS users employ to "make do."

2. Three views assessing the psychosocial effects of DBS

One way to describe the psychological and social problems some DBS users experience centers users' feelings of inauthenticity or alienation (Kraemer 2011a). Although people with conditions like PD and ET may encounter profound feelings of alienation or inauthenticity because of their conditions, Kraemer argues that DBS users may, similarly, feel authentic or inauthentic, alienated or more at home with themselves, as a result of using DBS. On her view, the experience of using DBS is a complicated process whereby users come to grips with how authentic (or inauthentic) and at home (or alienated) they feel using DBS around their friends and family. To understand why some people have trouble adjusting to life with DBS, it is important attend to how each user undertakes a process of "recognizing, exploring, and enacting what they regarded as their 'true selves'" (Kraemer 2011b, 496).

Take, for example, a person with a severe tremor who finds it difficult to eat without making a mess. Such a person might feel embarrassed eating at a public restaurant, and (as a result) they may feel less authentic to themselves than they did before the onset of their disorder. They may, further, feel alienated from their dinner partners and from onlookers. For people who feel this way, DBS may seem like a means of recovering lost ground if it successfully eliminates the tremor. But, if the DBS user experiences psychosocial side effects (e.g., increased impulsivity), they may feel even more alien or unrecognizable to themselves postop than they did pre-op. In her analysis of the now-canonical Schüpbach cases (Agid et al. 2006; Schüpbach et al. 2006), Kraemer (2011b) argues that some feelings of alienation are signs of progress (e.g., when a person feels alienated from their life with a movement disorder) and some feelings of authenticity cause problems (e.g., when DBS causes changes that users embrace but their loved ones are unable to accept).

While the language of authenticity might be useful for capturing salient features of DBS users' testimonies, it does suggest a problematic metaphysics of authentic selfhood. That is, if we take people literally when they say they feel "less like themselves," we may also (perhaps tacitly) accept that they feel authentic to or alienated from some predetermined "self." There are, of course, reasons to be skeptical of this claim: to say that a person has an "authentic self" is to draw a boundary around a set of attitudes, behaviors, and actions that constitutes a

person's self, but it would be difficult to draw such a boundary given how these behaviors change over time and across contexts. We accept, for instance, that we can act in completely different ways around different groups of people—who we are around our families is often different from who we are around our long-term friends. We would be hard pressed to say which of these "selves" is the "real" one—that is, insofar as one "self" takes precedence over all the others.[1]

Similarly, Françoise Baylis (2013) argues that DBS is not a threat to identity in the ways indicated by the authenticity view. Baylis, instead, takes on a narrative view of identity—where a person's identity consists of the ongoing story they construct about themselves. Self-narrative, she argues following Schechtman (2010), is too dynamic to talk about in terms of authenticity: who a person is changes with their lived experiences, the narratives they take to be constitutive of their identity, and the constraints placed on their self-narratives through their relationships with others. To this last point, Baylis asks us to consider the tension between how we describe ourselves and how others describe us: we cannot describe ourselves any way we want, and others cannot describe us any way they want. There is, in Baylis's terms, an "equilibrium constraint" on our self-narratives, whereby we negotiate with others to arrive at descriptions of ourselves that all parties involved can accept. "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" (Baylis 2013, 518). We might imagine that Baylis asks: what sense does it make to say a person has an "authentic self" when selves are so dynamic and constantly up for negotiation?

As such, Baylis takes a hard stance against the authenticity view: identity simply does not work this way, and to operate under the assumption that it does is to miss the details of how self-ascription works in its context: "it makes no sense to describe any particular event or experience (including DBS) as threatening. There is no pre-set autobiographical narrative (i.e., life story) that has been thwarted by some unfortunate event or experience. There just is the life story as it unfolds" (Baylis 2013, 516). That is, when DBS causes a change that makes its user feel out of sorts, DBS does not shift the user away from their authentic self. Instead, DBS simply causes yet another change in the user's ongoing autobiographical narrative. The DBS user may feel uncertain or upset about the self-narratives available to them, unsatisfied with the narratives their friends and family produce on their behalf, or uncomfortable "performing" any of these self-narratives (Baylis 2012). DBS implantation, Baylis argues, is not unlike other events (e.g., accidents, relationship loss, etc.) that have an impact on the stories we tell about ourselves.

There are cases, however, where Baylis admits that DBS constitutes a particular kind of threat to its user's identity on her view: "when DBS undermines agency to such an extent that the person is no longer able to meaningfully contribute to the authoring of her own life (i.e., to contribute to the cyclical and iterative process of projecting, defending and revising a self-narrative). Without the ability to contribute to the process of identity formation, a person loses the

ability to hold on to a sense of self" (Baylis 2013, 525). It is one thing, Baylis argues, for DBS to cause unwanted changes to a person that are then reflected in their self-narratives; it is another entirely for DBS to undermine a person's ability to make choices or form a self-narrative. Think, for example, of cases where people using DBS for PD develop gambling or risk taking behaviors. In such cases, users are rendered less able to make their own choices—they lose some of their control over their own behaviors, even as the system gives them relief from some symptoms of their movement disorder. These encroachments on the user's agency are the problem, not the mere fact that their self-narratives have changed in response to some important event. "When direct brain manipulation explains a belief or behavior there is reason to think of this as a serious threat to agency," she summarizes, "which in some instances may give rise to a threat to identity" (Baylis 2013, 524). As such, she concludes, "[These] disruptions [are] best examined through the *lens of agency*" (Baylis 2013, 514, emphasis added).[2]

Mackenzie and Walker (2015) extend Baylis's argument against the authenticity-view. They argue that "the appeal to authenticity . . . blurs the distinction between narrative identity and autonomy" (386): not only does the authenticity view obscure details about how DBS users (re)form, negotiate, and perform their identities, authenticity-talk also obscures the details of how DBS can impair or bolster the user's ability to act autonomously. To illustrate, they appeal to Walter Glannon's (2009) analysis of the aforementioned "Dutch patient," who faces a choice between keeping his DBS system turned on but needing to stay in a psychiatric facility to monitor stimulation-induced mania, or turning the system off but needing to stay in a nursing facility to receive care given his severely limited mobility. Glannon asks, "How much disruption can one's life narrative accommodate without threatening the integrity of the whole?" (291). Mackenzie and Walker (2015), in response, worry that "narrative reinvention of the self may not be possible" (382) when DBS "[disrupts] a person's autonomy competence to such an extent that he is unable to engage in narrative self-revision" (390). The salient issue for DBS—on their view—is autonomy competency.

That is to say, Mackenzie and Walker (2015) adopt and apply a relational, competency view of autonomy, on which autonomous agency "is a competence involving a complex repertoire or suite of reflective skills" (387). Among these skills are: the introspective skills necessary for knowing what we feel, need, and desire; imaginative skills that allow us to foresee possibilities for ourselves; communicative skills that make it possible to seek out and make sense of other people's testimonies and advice; volitional skills required to make decisions and follow through on them; and the interpersonal skills that help us form and sustain relationships (Meyers 2000, 166). On this view, in order to be autonomous 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" (Meyers 1989, 52–53). We cultivate our competencies in order to answer this question for

ourselves and act upon it. Further, crucially, our autonomy skills are developed, maintained, and exercised in the context of significant interpersonal relationships (Mackenzie and Walker 2015, 388). As Mackenzie and Walker (2015) apply this account, DBS is a threat insofar as it disrupts the user's autonomy competencies, rendering them less able (or unable to) employ these skills. In contrasting cases, when treatment with DBS is successful, DBS can help users regain the "volitional, emotional, motivational, imaginative, and critically reflective capacities necessary for autonomous deliberation and action" that were impaired by physical and mental illness (Mackenzie and Walker 2015, 390).

Some of Mackenzie and Walker's (2015) conclusions, however, seem out of step with the lived-experiences of the DBS users they consider. Is the Dutch patient well and truly "unable to engage in narrative self-revision" (390)? After all, given the choice between severe mania upon receiving DBS and debilitating Parkinsonian tremor without DBS, he was able to make the choice: he chose to use DBS, despite the onset of severe mania. That is, he chose to bring about a future for himself free of severe tremor, and we should not discount the importance or impact of that choice for him. Further, we cannot presume this is the end of the Dutch patient's ability to exercise agency. Encapsulated within these conclusions about the Dutch patient's decision—that he "sacrificed his mental competence and autonomy" (Kraemer 2013, 758), that he "is no longer able to contribute meaningfully to the authoring of [his] life" (Baylis 2013, 525; also quoted in Mackenzie and Walker 2015, 382)—is a misconception about the lives of people with psychiatric disorders. We should ask: Does the onset of a person's mania mark the end of their ability to "contribute meaningfully to the authoring of [their] life" (Baylis 2013, 525) through their capacity to act as agents (Mackenzie and Walker 2015, 390)? I argue that it does not. Instead, it marks the beginning of psychiatric treatment, more choices, and more decisions.

I agree with the move to frame cases like these in terms of DBS's impact on the competencies required for autonomous agency, but it is not clear that even the more severe side effects in these cases are so severe that autonomous agency is impaired or no longer possible. In order to be autonomous, we must be able to reflect on the options available to us, make a voluntary decision about what we want to do, follow through on that decision, and reflect on the consequences. For the Dutch patient, these competencies were made much more difficult to exercise: his mania might have constrained his autonomous decision-making abilities, but PD placed significant constraints on what he could choose. Even with these limitations, however, he retains the capacities necessary for agency—a person who intends and acts, even within significant constraints. In a way, it is less apt to say that the Dutch patient is *impaired* with respect to his autonomy competency: even the most competent of us would have a difficult time making the same choice. I argue it is more apt to say that the Dutch patient's competencies are *complicated* by DBS in a way that makes agency a struggle. We certainly ought to be able to make sense of how DBS impacts a user's ability to do the work required of being an agent, but we also ought to be able to make sense of

how DBS users are able to make use of or work around their neurostimulators in order to take on the work agency requires. In the next section, I'll present two cases that showcase several salient features of users' struggles with DBS.

3. The struggle of using DBS

A common conception of agency might maintain that a person expresses agency when their actions are initiated by the right mental states (Schlosser 2015). A more robust formulation of this conception recognizes that exercising agency is itself a skill—one cultivated through practice with and with help from others (Meyers 1989, 2000). That is to say, it can take work to figure out how to form an intention, work up a plan, and carry it out. After all, there are better and worse ways to decide between competing intentions, form plans, and drum up the motivation to act. Sometimes exercising agency is a struggle in and of itself, even if we table the possibility that some external forces can threaten autonomy. Motor and psychiatric disorders complicate that struggle, and DBS complicates that struggle further when it changes how its users are inclined to form intentions and act on them. The Dutch patient's experience is an extreme example of how DBS impacts agency—insofar as stimulation-induced mania changed how he formed intentions, insofar as his severe PD symptoms limited his available choices, and insofar as the juxtaposition of the two states was a challenge unto itself. DBS, however, can complicate even the average user's life: users will still need to choose stimulation settings, decide if and when to turn the stimulator on or off, determine if there are side effects, and so on.

Each of the views we've considered so far characterizes parts of the struggle DBS users face: when they feel inauthentic, are unable to contribute to their self-narratives, or are unable to make use of or further develop their autonomy competencies. Both Baylis (2013) and Mackenzie and Walker (2015), further, underscore the role interpersonal relationships play in these struggles. What is missing, I maintain, is an account of the mechanics of the relationships users form with the DBS system itself as they struggle against, alongside, and in tandem with it. One crucial feature of this relationship lies in how users come to rely on DBS in order to implement their intentions—despite how the system may not support the user as well in some contexts. Similarly, we rely on other people to support us agentially, even if it is possible for them to fail us. As a poignant illustration, Alisa Bierria (2014) argues that we rely on others to recognize the intentions behind our actions, even if they do not agree with or endorse them—"their recognition of our intention becomes a part of the social choreography of agency" (131). When others in our context do not recognize or validate our intentions, they may misinterpret our actions and constrain our actions as a result. But even under external constraints, it is still possible to exercise agency, and we are able to recognize these exercises when we take up "a reimagining of agency that foregrounds the experience of 'struggle' when trying to accomplish an end and emphasizes the role of improvisation and making do when there is a breakdown of an agentic plan" (Bierria 2014, 137). Bierria,

here, borrows this last insight from Susan Wendell's (1989) exploration of what feminist theory can learn from the lived-experiences of people with disabilities, and she does so in order to "trouble an idealized notion of agency that hinges on efficacy" (Bierria 2014, 142–43).

Using DBS (in some cases) requires just this kind of improvisation and making do under the constraints of systems users would like to be able to rely on. That is, when DBS does not work the way the user expects and there is a breakdown of their agentic plan, the user will need to improvise (perhaps devising a way to work around the problem) if they want to carry out an agentic plan at all. But, where Bierria retreats from the relational for the sake of making sense of how agency is possible without uptake from (or in defiance of) oppressive others, I embrace the relational for the sake of making sense of the lived-experiences of people using neuromodulation. Instead of asking if (and how) DBS poses a threat to the user's agency, I ask: what are the mechanics of DBS users' confusions, negotiations, and collaborations with their neurostimulators?—and how do users express agency throughout? For the remainder of this section, I'll present two of the many possible challenges DBS users could face as they struggle with, against, and alongside their stimulators. For the first, users find it difficult to determine the source of their behaviors. For the second, users must make the tradeoff between DBS's side effects and the effects of the disorder treated.

3.1. Agency ambiguities and psychiatric disorders

In a focus group conducted with people participating in a research study focused on using DBS to treat their treatment-resistant clinical depression, Klein et al. (2016) found that a number of participants expressed worries over what the authors termed *ambiguous agency*—or the possibility "that individuals with DBS might lose track of their sense of agency if it became unclear whether they or the device was responsible for their feeling or acting in a certain way" (4). One participant describes it:

> I've begun to wonder what's me and what's the depression, and what's the stimulator. I mean, for example, I can be fine, and then all of a sudden . . . I'll say something that is insensitive or just misread a person entirely, say something that either makes ME look like a fool, or, hurts them, or, something along that line. I can't really tell the difference. There are three things—there's me, as I was, or think I was; and there's the depression, and then there's the device and . . . it blurs to the point where I'm not sure, frankly, who I am. (Goering et al. 2017, 63)

Another participant framed this concern in terms of how others think of their DBS use, "So, there's people in my family that sometimes question . . . how much of it is me any more and how much of me is . . . bein' programmed. So that's been a . . . that's a hard thing to deal with sometimes, but, you know, like I said, I'll take it over what I had" (Goering et al. 2017, 5). A third participant tried to

imagine what their behaviors would have been without DBS, "There are parts of this where you just wonder how much is *you* any more, and you wonder kind of, 'How much of it is my thought pattern? How would I deal with this if I didn't have the stimulation system?' You kind of feel artificial" (Goering et al. 2017, 5). In a later analysis of these focus group data, Goering et al. (2017) report one user's difficulty determining why she could not cry at a funeral: her life's circumstances, her drug prescriptions, or her stimulator's settings (63).

In a series of interviews of people using DBS for OCD, Haan et al. (2017) found that a number of participants "had to get used to themselves, their new lives, and their new behaviour" (14). Many of their experiences share much in common with the participants in Klein et al.'s study. According to De Haan et al. (2013), "the majority of the participants (12) had been thinking about the question of how to determine whether the changes that accompanied the DBS treatment were side-effects or rather reflections that they were becoming more themselves" (17). One interviewee remarks on how their interpersonal behaviors have changed: "From always making up excuses, never being able to keep appointments . . . . And then I just say: 'Yes, sounds fun'—and then I think 'Is that me?' A bit strange, really, I need to get used to myself too" (14). Another reflects on how they've lost friends after using their implant, "I think that I just, yes, stand up for myself more. And for some people, that is just not comfortable; the relationship [with them] just changes because of that. . . . What I also have, and that also bothers me a lot, is that my interest in the people around me has decreased significantly. . . . I am still not used to it" (15).

We might characterize these users' remarks as indications that DBS changed their *sense of agency*—"the sense that [they are] the one who is causing or generating an action" (Gallagher 2000, 15). This sense of agency typically includes an understanding of ownership or "'mineness' for one's body and actions" (Gallagher 2018). The impact of DBS on the user's sense of agency might be even more profound so as to disrupt or supplant the user's agency when they act in ways they cannot claim as their own (Lipsman and Glannon 2013). We must remember, however, that if a person uses DBS to treat their depression or OCD, then they necessarily mean to change features of their agency—they, after all, want to act in a way less impeded by their depressive episodes or their obsessions and compulsions. That is, to treat a person's psychiatric disorder is to prevent unwanted intentions and actions—it is an intervention on their agency. And, if we start from an enactive, embodied perspective, as de Hann et al. (2013) do, we start by considering "the whole complex system of a person interacting with the landscape of affordances" (12). These systems, if they work, are meant to change crucial affordances available to users (Haan et al. 2013, 2017; Gallagher 2018). But those changes can only happen in light of substantial changes to how they exercise their agency.

Even still, such users, as the participants in Klein et al.'s (2016) and De Haan et al.'s (2017) respective studies demonstrate, may not feel they are the sole source of their own actions, even if they previously intended to bring about

and currently endorse these changes. Even if the user's new behavior is precisely what they wanted, currently want, and need for their own continued survival, the very fact that neuromodulation is the cause of their personality changes may challenge their beliefs about the relationship between their brains and their behaviors (Mecacci and Haselager 2014), or change the way they approach situations. As such, these feelings of ambiguous agency could have an effect on users' actual exercises of agency in several ways. Users may be less inclined to hold and act on intentions if they cannot be sure they are the source of those intentions. Further, they may be less willing to take responsibility for actions resulting from those intentions if they don't feel that their actions are their own (Klaming and Haselager 2013; Sharp and Wasserman 2016). But lastly, these ambiguities make it difficult to determine what to do next.

To underscore the problem raised at the end of the last section: where DBS gives the user the ability to act in ways their psychiatric disorder would not allow, the salient question may not be, "Does this system threaten the user's ability to contribute to their identity-constituting narratives?" The answer to this question may very well be "yes" for as long as the user experiences these difficulties. But such DBS users are not rendered powerless. To the contrary, the experience of agential ambiguity is a challenge to the user's agency—a challenge they must address in order to see therapeutic benefits. The woman who found herself unable to cry at a funeral also found it difficult to determine what kept her from crying and what to do about it. She is not rendered powerless, but her agential power is made complex through neurostimulation. Even if the user would "take it over what [they] had" (Klein et al. 2016, 5), these complications to users' sense of agency make up a terrain that takes skill to navigate.

3.2. The tradeoffs of DBS for Parkinson's disease
People with motor disorders like PD face analogous complications to their agency, but their struggle might more often require making sense of how DBS limits or extends their control over their bodies. Consider the case of Helmut Dubiel, a professor of philosophy who lived with PD and used a DBS system to manage his symptoms. Stimulation came with a variety of side-effects: a severe speech impairment, exhaustion, and depression. He writes: "My worst post-operative symptom, which remains unchanged to this day, is a speech disturbance: my volume is too low, and my articulation is poor, slurred" (Dubiel 2009, 94). This side-effect made it difficult for Dubiel to work as a professor—to give lectures or speak with others. Further, he tried to keep his diagnosis private—it was a secret that he believed would, at least in part, "discredit [him] in the eyes of the world" if revealed (94). But PD is a degenerative disease; its symptoms worsen over time: he could only conceal those symptoms for so long before they became too apparent. DBS might have given him another means of managing (and thus concealing) his symptoms, but it also complicated Dubiel's already complicated expressions of agency.

Dubiel was only able to get a handle on his stimulation-induced speech impairment once he sought out the help of a neurologist and representative from the device's manufacturer. They determined that stimulation was, indeed, the cause of his difficulties speaking. "It was as if I were channeling a spirit," he says, describing the moment the DBS was turned off, "that very second my voice returned, sonorous and clearly enunciated, only slightly hoarse" (Dubiel 2009, 118). He received a *patient programmer*, a handheld device that allowed him to turn his device on and off. This, then, gave him the ability to choose between treating his motor symptoms and speaking without an impediment.

As such, Dubiel could exercise his agency and make choices about his treatment, even as the device constrained his available choices. Baylis (2013), reflecting on her conversations with Dubiel, underscores the system's positive impact on Dubiel's outlook: "While having to choose between talking and walking is less than ideal," she writes, "Dubiel's restored ability (within limited parameters) to control his body in social situations restores his pride and professional authority" (521). She characterizes Dubiel's struggle with his DBS (and with PD in general) in terms of his ability to construct his identity-constituting narratives given the constraints of PD. "Dubiel is the person at the intersection of who he wants to be, and who others will minimally let him be," she concludes (521). This description, while useful, leaves us with a blind spot. DBS itself is also constraint on who Dubiel wants to be. As such, he is also what his DBS will allow him to be through his successive attempts to navigate the device's settings, their impact on his behaviors, his (and others') reflections on the device, and so on.

4. Neurostimulators as relational agents

The views we considered earlier could lead us to say that neurostimulators are inert devices that can cause changes in users that confound or bolster key features of their selfhood. DBS is considered a threat when it undermines a feature of the self the user wants to preserve. The examples we have considered, however, suggest that interactions between DBS and their users are more negotiative and collaborative than previously acknowledged. They frame users' interactions with their stimulations in relational terms. We only need fill out the details of this relationship.

Let's grant, as Baylis (2013) does, that our narrative identities are constituted relationally through an "iterative process involving 'self'-perception, 'self'-projection, 'other'-perception, and 'other'-reaction" (514). Further, let's grant, as Mackenzie and Walker (2015) do (following Meyers [1989]), that our autonomy competencies are cultivated in part by and through our relationships with others. It is not a stretch to say that parts of ourselves are cultivated through our interactions with technology, constituted through our iterative relations to devices.[3] Neither is it a stretch to say that our autonomy competencies are cultivated by and through our relationships with devices. We need only give a more robust framework for thinking about the details of these relationships.

First, consider how relationships work between humans given how we create identities that we enact in the world. Hilde Lindemann (2014), in her *Holding and Letting Go*, defends a relational view of identity that underscores how others (family and friends most often) play an active role in constructing our identities as well as with supporting and resisting our attempts to express them. This process of "ordinary identity work" (94) involves a kind of performance, making use of a shared corpus of narratives held about one another as the springboard for improvised action. We build as well as enact our identities socially. "It's an act," she maintains, "a kind of theatrical performance" (98) wherein performers use their knowledge of themselves, their fellow actors, and the social context to determine how to express themselves. Further, stage actors perform for audiences, and our expressions of personhood are similar: "as we express ourselves, others will in turn have to be impressed by us in some way" (98). Even further, each performer relies on their fellow performers to respond appropriately: "[Other actors'] job is to perform the 'response' moment of personhood, which they do by taking up the dual role of audience and performer" (99). By following the rules recognized within the social context the actors are in, and acknowledging when their fellow actors perform appropriately, each actor performs a normative role. We hold each other in our respective identities as we perform (or express) them together in a variety of contexts.

We must remember, however, that performance is difficult, and sometimes our fellow actors could do a better job of giving us the uptake we require to perform our identities well. Bierria (2014) demonstrates how our fellow actors can oppress us through their misinterpretations of our actions (and the intentions behind them). Lindemann (2014), similarly, notes that when our fellow actors are inexperienced or unfamiliar with us, we may have to "engage in what has been called the 'hidden labor' of manipulating the others into giving her the proper response" (101). If a more experienced actor is paired with a less experienced one, they may need to "carry" the performance for their partner—by making it obvious where their partner should be in the script, exaggerating their performance so that their partner emotes appropriately, and so on. She gives the example of Jackie Leach Scully's (2010) experiences traveling with a hearing impairment: "she has to 'perform deafness'—for instance, by cupping her hand behind her ear and looking quizzical—if she's to convince flight attendants that she needs special notification of in-flight announcements" (101). Scully had to exaggerate her own performance to pick up the slack from the flight attendant—who is not accustomed to performing with people with hearing impairments.

Similarly, DBS users may need to "pick up the slack" for their DBS systems when they are not optimized. Dubiel (2009), for instance, wanted the opposite of what Scully did: he wanted to keep his symptoms hidden from view. He found this difficult to do not only because of the expectations of his friends, family, students, and colleagues. He also struggled against, with, and alongside his Parkinsonian symptoms (first and foremost), his neurostimulator, and the medical professionals who were responsible for maintaining his neurostimulator

system. The outcome of Dubiel's attempts to conceal his disease was contingent on his ability to improvise over his Parkinsonian symptoms, negotiate with the device's manufacturers, and control the neurostimulator's settings (once given the means to). Dubiel had to *carry the performance* despite his stimulator's inefficiency. Similarly, the participants in both Klein et al.'s (2016) and De Haan et al.'s (2017) respective studies describe being uncertain about being the source of their own actions, needing to get used to who they are while using DBS, and having to convince others to accept their new behavior. If DBS systems play some role in the mechanisms of their users' ability to form intentions and carry them out—and surely, in the case of psychiatric disorders, they must—what role can we say DBS plays in how they perform their identity? Is DBS a prop or a character?

We can begin to answer these questions if we attend to the possible status conferred upon DBS systems through users' interactions with them. Although the DBS systems may appear inert, perhaps they gain a kind of conferred animacy, given how it intimately they interact with the users in ways that impact their agency. In her "Vital Wheels: Disability, Relationality, and the Queer Animacy of Vibrant Things," Julia Watts Belser (2016) argues that wheelchairs—thought normally to be "dead matter" by the able-bodied—take on a kind of "animacy" through interactions with users. On her view, "wheelchairs occupy an intimate space: simultaneously an expression of our own body-forms and a distinct, independent entity—a vital, vibrant being" (7). That is, the wheelchair is not just dead weight pushed around by some wheeler; rather, the wheelchair takes on the wheeler's (expressive) movements in some moments, resists movement in others, and sometimes seems to have a character of its own. For Belser, then, wheelers and wheelchairs can form an "*intricate partnership*," or a "mutuality between wheeler and chair [that] demands an understanding of how hand and tire interrelate, how weight affects wheel. Motion and presence are unified; the self is expressed in and through wheels" (12, emphasis added). Given the structure of the relationship between wheelers and their wheelchairs, Belser insists it makes more sense to say that the wheeler and their chair act together than it does to say the wheeler pushes their chair.

Belser, however, more often reaches for examples of competent wheelers who contend with and relish the quirks of their wheelchairs. By acknowledging the animacy people with disabilities confer on their wheelchairs, she elevates the status of both people with disabilities and the tools they rely on above that of dead weight. This move preemptively counteracts prevailing ableist attitudes that would characterize people with disabilities as with significantly diminished agency or without agency at all. By attending carefully to how disabled people express their agency in partnership, we are able to understand more clearly how thoroughly relational and socially embedded agency is writ large. In this way, Belser's project lines up with Bierria's: both problematize oppressive misinterpretations of agency by showcasing oppressed peoples' powers as agents. I want, however, to recognize those moments when we use our technology in a clumsy

or awkward way so that we can also attend to how we become competent or graceful through an iterative process of cultivating the skills necessary (i.e., for gaining agency competence).

DBS and their users, I contend, occupy a similar shared space in moments of struggle. We can see this most clearly in the moments where users try to figure out what role DBS will play in their lives and what role they want DBS to play. Goering et al. (2017) argue that we should think of these systems as relational others in just this way—as systems designed to supplement or support an individual's agency the way a friend or family member would. Just as friends and family enforce the reality constraint on our identity–forming narratives (Baylis 2013), related others also hold us in identities during our performances of them (Lindemann 2014). Related others hold a great deal of power on this view: the right other, in the right position, can often notice changes in me that I cannot see, and they can (perhaps) influence me in ways I am unable to perceive. As we have seen, DBS can influence users similarly: producing changes at a neurological level that are sometimes easy to notice (e.g., when it treats tremor) and sometimes are not (e.g., when it induces mood changes). And just as it is often necessary to set boundaries with controlling friends and family members, it might be necessary for the DBS user to set goals for and boundaries on how their stimulator impacts their agency. To make sense of this boundary-setting, we need to take seriously the possibility of relational forms of agency where "an individual's agency (connecting her motives and actions) can be supported through and entwined with a variety of external others" (Goering et al. 2017, 66)—even if those external others are not so external to us, even when they are, in fact, devices implanted in our bodies.

In order to understand users' lived-experiences of coming to grips with the realities of stimulation, we must attend to the "mutuality" between neurostimators and the stimulated. Many features of life with DBS are salient here: the subcutaneous space the leads and stimulator unit occupy, the maintenance required to prolong battery life or ensure the system's efficacy, the physiological and psychological effects (intended or otherwise), the need to negotiate tradeoffs or "workarounds" to problems (should they arise), how family and friends think about stimulation, the option to change stimulator settings, one's reflections on life with such a system, and so on (Brown et al. 2016). User experiences will vary, of course, but we can say at least this much: many of these experiences require "getting used to," while others will require sustained negotiation to figure out how to live and work with DBS. Dubiel's negotiations were iterative and ongoing as he learned how his stimulator's voltage levels match up with his symptoms and social context. A user navigating "agency ambiguities" has work to do as well: learning what role their stimulator plays in their behaviors and determining what role their stimulator will play in future behaviors.

Earlier, we asked what role DBS plays in users' performances of identity: are they props or fellow agents? Our best answer, for the moment, is that they are somewhere in between. Users confer animacy on their stimulators through their

attempts to express themselves with the help of stimulation. When difficulties arise, users must negotiate and collaborate with their stimulators to overcome them. In the future, however, we may have grounds to call neuromodulators full-fledged agents. Currently, neuromodulation systems are configured manually by technicians, neurologists, and (in a growing number of cases) users. Several groups, however, are testing artificially intelligent DBS systems capable of adjusting themselves. Such systems would record and analyze data recorded from sensors implanted in contact with a user's brain in order to determine when to (or when not to) apply stimulation (Hebb et al. 2014; Klein and Nam 2016; Goering et al. 2017). Such a system could present users with even more difficulties. Imagine, for instance, if Dubiel's stimulator were able to detect when he wanted to speak or when he wanted to walk. Such a system could have been convenient—insofar as Dubiel would no longer need to use explicit commands to control his stimulator. It might have also been more difficult—insofar as Dubiel might have had trouble predicting when the system would switch states, determining what the current state of the system is, and so on. These systems, we might say, act on their own. As such, we might be inclined to say that such systems are not just conferred animacy but, instead, are much more agents in their own right (Klein et al. 2016; Kellmeyer et al. 2016; Goering et al. 2017; Yuste et al. 2017). How often will DBS users need to "carry the performance" for their artificially-intelligent neurostimulators, or will they be "held" too tightly by them?

In summary, I've suggested that DBS is capable of more than just bolstering or threatening user agency. On my view, users are capable of conferring animacy on their DBS systems, and DBS systems are capable of holding their users to certain performances of agency. As such, users form an intricate relationship with DBS that can be challenging and require skill to navigate in difficult circumstances. But what skills do users require to do well in these relationships, and how do they cultivate these skills? In the next section, I explore this question and identify skills users might train as they build relationships with DBS.

5. Agentic skills for relational agency

Earlier on, I suggested that we should think not only about DBS's impact on autonomous agency but also its impact on agency broadly. I continued to say that agency itself a kind of struggle—a struggle made more complicated by DBS and the relationship formed with it. Both Baylis (2013) and Mackenzie and Walker (2015) remind us that our autonomy competencies are cultivated and exercised relationally. But, if my proposal above is correct, the DBS user's answer to the question "what do I truly want?" is, in some cases, the product of the collaborative partnership between then and their stimulators. Below, I'll gesture toward three skills that we might be able to identify as users navigate their partnerships with DBS: *introspective vigilance*, *improvisation*, and *relational resourcefulness*.

Some of the difficulties with DBS are a result of the user not being able to determine where their agency ends and the DBS's intervention begins. The

case of the woman who puzzled over why she could not cry at a funeral is a clear example of this dynamic. Her worries themselves, however, are an example of an *introspective vigilance* where she is "attuned to signs of frustration and dissatisfaction, attentive to baffling subjective anomalies, and willing to puzzle out gaps in one's self-understanding" (Meyers 2000, 167)—this could be a useful strategy for making sense of her relationship to DBS. That is, her worries about her behavior, her behavior's possible causes, and what she ought to do in response, are apt and crucial to taking control of her experiences. Being aware of the change in her behavior and knowing that it could be related to stimulation is an important first step. This kind of vigilance motivated Dubiel (2009) to insist that his DBS was causing many of his cognitive and speech issues, and he was eventually able to gain control of his stimulator enough to confirm his suspicions and tune his stimulation to match his needs.

In moments when DBS performs in a clumsy way[4] and when the user's agentic plan does not pan out, *improvisation skills* can help smooth the performance over or devise solutions to problems. Recall Dubiel's attempts to conceal his PD symptoms. In moments when his stimulator induced a speech impediment, he chose words he could say despite his impediment in order to perform agency in ways that are more in line with his intentions.[5] Further, the woman who could not cry at a funeral might need to improvise a way to express the emotions she wants to express and to mourn the way she wants to mourn.

Finally, cultivating a kind of *relational resourcefulness* can help the user situate DBS alongside the other resources they can use to support their expressions of agency. Recall the problems DBS users' friends and family members face as they grow accustomed to how DBS changes the user's moods and behaviors. One study of people using DBS for PD found evidence suggesting that friends and family notice personality changes more readily than the users themselves (Pham et al. 2015). This suggests that users may need to rely on friends and family to inform them of these changes. Some users may not want this kind of feedback—for example, when the user has family members who think adjusting the stimulator is a solution to all of the users' problems (Klein et al. 2016). Other users, however, may be able to make use this feedback to improve their relationship with DBS—that is, friends and family can make themselves useful by learning how DBS works, by noticing side-effects, by corroborating the user's worries, by advocating for the user, or just by being understanding when the user's agentic plan falls flat.[6]

6. Conclusions

My central claim has been that DBS systems are relational partners insofar as users cultivate relationships with these devices as they perform agency through their use of them. I considered several views that attempt to make sense of the ways that DBS systems change their users' lived-experiences, and identified several problems within them. Chief among these problems was the tacit assumption that, in extreme cases of personality change, DBS users lose their identity

or agency as a matter of course. To address this problem, I proposed that our view of agency should capture the struggles people have with their stimulator devices, and their attempts to "make do" with them.

After considering two key examples of the relationships users have with their neurostimulators, I offered a synthesis of several views to frame and characterize these struggles. On my view, DBS systems are capable of holding us—helpfully or disruptively, depending on the context—to certain performances of agency. As such, some users form (or will have to form) intricate partnerships with these systems in order to make use of them. Through these relationships, users may confer animacy on these technologies to the point where their exercises of agency are supported, encumbered, and otherwise "intertwined with" them.

Finally, I identified skills that users can and already do use to navigate challenges with and alongside DBS. In the end, we are left a view that—I hope—promotes DBS from the status of an inert device that either enables or confounds its user's agency, to the status of an interactive system with which users collaborate. Further, and more important, we are left with a view that promotes the DBS user from a vulnerable target for potential threats, to an (at least partially) empowered agent.

NOTES

1. Perhaps there are even metaphysical and (by extension) epistemological difficulties when we presume that we have selves that are unified enough to call "authentic" in the first place. Specker Sullivan (2019) explores this possibility and its implications.
2. Also see Goddard (2017), who also calls for framing the users' experiences of DBS through "the lens of agency."
3. Others, Andy Clark (2008) and Andy Clark and David Chalmers (1998) most notably, go further to say that cognition can extend into the technologies we use, if those technologies stand in the right relationship to us.
4. I borrow this turn of phrase from Lindemann (2009), where she describes how people with dementia hold their friends and family—dementia makes holding difficult, and so people with it hold their loved ones to the best of their ability, clumsily.
5. This could, however, be a converse (but also problematic) form of Scully (2010) performing deafness for the sake of prompting others for assistance. The implications of Dubiel's (2009) attempts to "pass" as able-bodied, in the broader context of ableist attitudes about and stigmas against disability, deserve their own investigation.

6.   Fins (2018), relatedly, proposes a *mosaic approach to decisionmaking* for people using DBS to counteract injury-induced minimally conscious state (MCS). As the injured person's agency reemerges, Fins argues, they will need the assistance of several other agents—a surrogate, medical professional, and an advocate—that form a mosaic of agents that make decisions together.

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