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In Pursuit of *Agency Ex Machina*: Expanding the Map in Severe Brain Injury

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Schönau and colleagues (2021) are to be congratulated for their multivariate effort to map elements of agency providing a comprehensive framework for clinical application and normative research. In our peer response, we would like to add to the three hypotheticals they present (BCI in spinal cord injury, BCI in ALS and closed loop for DBS in Major Depressive Disorder) and apply their map to the work we have done developing central thalamic stimulation (a form of open loop DBS) initially in the minimally conscious state (MCS) (Fins 2015; Schiff et al. 2007) and most recently in moderate to severe traumatic brain injury (msTBI) (Schiff et al. 2019) as part of the BRAIN Initiative.

Our work has sought to map the neurological circuitry of these disorders as well as the ethical terrain of intervening in the injured brain (Fins and Shapiro 2014; Schiff 2010). In this essay we turn our attention to Schönau et al.'s *normative* map and identify the limits of analogic reasoning (Sherwin 1999) applying their normative framework to conditions where agency has been lost entirely as in patients who are unable to communicate in MCS. A second distinct category are patients with msTBI whose agency has been compromised from the sequelae of chronic brain injury. Through our inquiry we hope to broaden Schönau et al.'s cartography to these two cohorts of TBI patients. These patients will benefit from *both* Schönau et al.'s map and as well as a moral compass to navigate their way back to agentic capability.

While we appreciate the prudential ethic of Schönau et al. mapping the threat that neuroprosthetics can pose to authenticity, privacy, trust, and responsibility, we would hesitate

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to overstate their putative burdens. In doing so we risk failing to acknowledge the potential of these devices in moderate and severe brain injury.

Patients with severe brain injury are quite different than those with high spinal cord injuries or depression. Drawing upon experience piloting DBS in disorders of consciousness and in msTBI, we have observed that the greatest threat to agency is not the neuroprosthetic itself but rather the lack of a therapeutic intervention that can foster reemergent agency once it has been lost (Fins 2018). Given this, any calculation of proportionality and the burdens and benefits of a neuroprosthetic will look quite different.

To refine our analysis, let us consider the four points of the moral compass offered by Schönau et al. Let us begin with authenticity. While the authors worry that a neuroprosthetic might lead to a risk of inauthenticity, in our investigative experience with DBS in MCS and msTBI, thalamic stimulation was restorative, leading to a more authentic presentation of the self. For example, the mother of the subject featured in our 2007 *Nature* paper describing thalamic stimulation in MCS (Schiff et al. 2007) reported that following the activation of the stimulation, her son was “still Freedom,” the nickname that he carried as a younger man (Fins 2015).

Before he was stimulated, the extent of his interaction was episodic and intermittent responses to verbal stimuli with occasional eye movements. He couldn’t speak or voice a preference. He had completely lost any sense of agency. But with the stimulator, he was able to say six of seven word sentences, tell his mother he loved her, and say the first 16 words of the U.S. Pledge of Allegiance. He could accompany his mother to an Old Navy store and voice a preference about clothing. Once, when we were doing post-study stimulation parameters, a member of our team asked him if he wanted to stop and take a break and he said yes (Fins 2015).

These examples indicate the restoration of agency from a neuroprosthetic device, *agency ex machina* if you will. But most important was what his mother said about him. Through stimulation his personality had come back and he was still Freedom, an ironic name as it suggested that he had been liberated from the confines of his injury and given the liberty to return to some semblance of his former self, a self that a mother could recognize and *authenticate*.

In our current trial of DBS in msTBI, we have interviewed subjects and their family members before and after stimulation. One area of inquiry is precisely the question of authenticity. While we await the completion of the study to engage in a formal analysis of our transcripts, subjects and family members report movement toward the restoration of the pre-injured self with respect to improved cognitive abilities and increased social engagement (Wright and Fins 2021).

One subject who received DBS for cognitive impairment following msTBI reported that with the changes evoked by stimulation, they¹ needed to reenvision their goals and find “new friends” with whom they would be more compatible. This desire to expand one’s

¹In order to protect confidentiality, they is used as a pronoun.

scope of friends was more reflective of wanting to reengage peer groups with whom the subject would have interacted prior to injury. A child of another subject reported that following stimulation a parent was more familiar, like their old self. Both these cases indicate a more authentic self with stimulation rather than the reverse.

The authors rightly raise questions of decisional privacy, a point of theoretical relevance when considering whether to interrogate the brain for evidence of covert consciousness in a patient thought to be vegetative. Practically, and of greater normative concern, is whether through misdiagnosis or disinterest we have mistakenly categorized a sentient person as unconscious. Such a nosological error could destine a patient to isolation in a private hell. So sequestered, they would be unable to communicate and thus excluded from communication's cognate, human community perhaps made accessible through the intercession of intracranial BCI or perhaps DBS if recovery of speech or gesture allowed reestablishing functional communication. While there is a putative risk of a privacy breach, it is a concern that could be regulated. Isolation inside's one head, and the deprivation of community, seems a greater burden than any hypothetical concerns about neural privacy.

Moreover, with the restoration—or facilitation—of communication, one could ask an individual for ongoing consent or assent (depending on capacity assessment made possible by the neuroprosthesis) to continue stimulation. This would build trust in trial participation and provide the discursive substrate to help subjects gain trust in their devices. Our point is that restoration of agency, and facilitated communication, are *preconditions* for consideration of any subsidiary issues, including trust.

Turning to the question of responsibility, it seems to us that Schönau et al. overly focus on accountability for motoric actions. They offer as an example an injury to another's outstretched hand when a neuroprosthetic arm squeezes too tightly. The emphasis is on acts of commission, when the subject may or may not be responsible for outcomes that could lead to harm. But what of acts of omission by the investigative and clinical community when we neglect persons with TBI who may have thoughts they are unable to communicate? Or when they are unable to communicate in an effective or timely manner? Here we want to focus on the responsibility of clinicians and investigators to intercede and give voice to those who may yet be able to communicate and engage with the world in the case of MCS patients or reestablish their greater participation in society as in the case of those with msTBI. Once that effort is successful, one could turn to questions of a subject's responsibility for their discourse. Although it is tempting to ask whether subjects would be able to properly filter their thoughts before they became speech, improved agency and the autonomy provided by speaking versus being permanently silenced is the greater ethical good (Fins 2017). A neuroprosthetic would help achieve these goods.

We are grateful to Schönau and colleagues for their efforts to map the normative dimensions of agency. Here we sought to expand the map to a wider range of patients with disorders of consciousness and those with msTBI in order to illustrate how their topography differs from other conditions. For this historically neglected population it is especially important that any analysis does not inadvertently perpetuate neglect. By focusing on fears about emerging

prosthetics we could well extinguish hope for those whose lives could be made better by technological advance.

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