RESEARCH AND SCHOLARSHIP

OVERVIEW

CNT research includes:

- Focus groups with individuals with disabilities on perspectives of brain-computer interface (BCI)
- Focus groups and interviews with end users of neural devices
- Interviews with subjects with closed-loop deep brain stimulation (DBS) for essential tremor (Tim Brown) and with subjects with DBS for depression and obsessive-compulsive disorder (Eran Klein)
- Survey of BCI scientists on attitudes toward ethics and ethics engagement
- Collaboration with the Neuroethics Core at UBC

RECENT PUBLICATIONS

FORTHCOMING


2019


2018


2017


Klein, Eran. "Who invited the clinical neuroethicist?" *Journal of Hospital Ethics* 4, no. 2 (2017): 60-64. ISSN 1938-4955


2016


**PRESENTATIONS**


Specker Sullivan, Laura. “Normality Through the Lens of Neural Engineering.” Paper presented at the International Conference of Japan Association for Philosophical and Ethical Research in Medicine, 2015.
GRANTS


(PIs Goering and Klein; partners at Freiburg University, Cal Tech, Brown University, and Utrecht University; $1.3 million over four years)

Abstract: Neural prosthetic devices for sensorimotor and psychiatric disorders are in development as a priority area of the BRAIN Initiative yet they raise important ethical concerns about human agency. Agency, our ability to act and to take ownership of our thoughts and actions, is central to individual identity and moral responsibility. Although concerns about agency are often raised in the literature on neural prosthetics, agency remains a complex phenomenon that is (1) poorly understood, (2) difficult to study through quantitative or one-off qualitative “outsider” methods, and (3) without resources to help research participants understand agency side effects and engage in meaningful informed consent.

In this project, we aim to address these gaps. We will (1) conduct a comprehensive survey of the relevant literature on agency and neurotechnology in order to construct a concept map of neural agency, (2) use a longitudinal and phenomenological interview method to better understand and explore user perspectives on agency, and integrate those perspectives into a user-centered neural agency framework, and (3) develop a communication tool (a question prompt list or QPL) that research participants and patients can use to understand and discuss potential agency effects of neural devices during the informed consent process.

NIH ETHICS SUPPLEMENT (2018-19): PARENT GRANT (AT MASSACHUSETTS GENERAL HOSPITAL): COMBINED CORTICAL AND SUBCORTICAL RECORDINGS FOR THE TREATMENT OF OBSESSIVE COMPULSIVE DISORDER

(PIs Dougherty and Widge). The ethics supplemental grant involves interviews with users of these neural devices for OCD and their closest family member, to better understand the experience of using the device, in relation to issues of agency, identity and privacy. (Co-investigators, Goering and Klein; RA Boulicault)

Abstract: The current project aims to understand the neural circuits underlying OCD but also to understand how DBS technology affects people in their daily lives. One central area that gives meaning to people's lives is their relationships with family members and loved ones. Little is known about how family members understand DBS in psychiatry, their expectations for its effects, and their satisfaction with implanted devices (and the changes that occur in their loved ones). This project will include interviews with patients, families, and psychiatric DBS researchers in order to understand how family pre-implant expectations influence the informed consent process and how family post-implant experiences modify patient satisfaction with adaptive DBS.


(PIs Baltuch and Gold). The ethics supplement looks at questions of expectations regarding research, participant conceptions of mind and experience during awake portions of DBS surgery, and sense of agency while using the DBS device.

Abstract: This proposed research supplement examines patients’ intraoperative experiences during awake deep brain stimulation (DBS) and the parent grant’s decision-making task itself. DBS surgeries that involve awake phases are increasingly common yet there is surprisingly little empirical attention to patient experiences of the intraoperative awake phase of the DBS or other neural implant surgery. Given evidence that a significant number of patients experience psychological or somatic effects of this phase of surgery, more attention ought to be given to patients' intraoperative experiences. We will conduct a mixed methods study of patients participating in awake surgery, exploring motivations for research participation, expectations about the awake surgery, the phenomenological experience of awake surgery, and sense of agency/identity.

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