A Systematic Review of Stakeholder Perspectives on Cognitive Effects of Brain Stimulation

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Introduction

Brain stimulation (e.g. DBS, tDCS, etc) is an emerging technique for the treatment of neurological and psychiatric conditions. Despite its promise, there is an accumulating body of literature on unintended motor, psychiatric or psychosocial effects of neurostimulation. Changes to language, memory, and other cognitive processes, on the other hand, have been relatively understudied and underreported by patients, caregivers, and healthcare providers. This trend parallels an increased scientific and medical interest in the use of brain stimulation to treat disorders of cognition, such as dementia.

Systematic reviews of brain-computer interface (BCI) studies using social research methods have proven useful to guide further qualitative research on patient experience. However, brain stimulation and its cognitive effects have not been the focus of such reviews.

Aim: Characterize actual and expected cognitive effects reported in previous qualitative literature on brain stimulation.

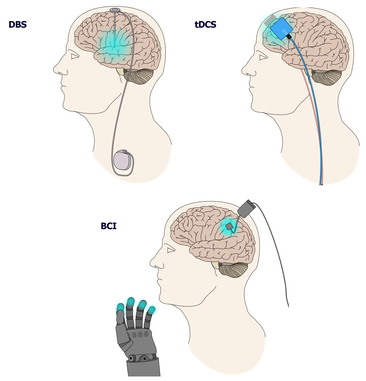

Figure 1. Different types of brain stimulation. (Top, Left) Deep brain stimulation. (Top, Right) Transcranial direct current stimulation. (Bottom, Left) Bidirectional brain-computer interfaces for sensorimotor feedback (Bottom)

Methods

A PubMed database search for qualitative studies on brain stimulation yielded 34 unique datasets from 41 publications that include quoted responses to open-ended interview or survey questions.

Primary Search: ((brain stimulation)) AND ((perspective OR perspectives) OR (opinion OR opinions) OR (view OR views) OR (interview OR interviews) OR qualitative)

Secondary Search: (((“responsive neurostimulation”) OR (brain computer interface OR brain computer interfaces) OR (brain machine interface OR brain machine interfaces) OR transcranial direct current stimulation OR transcranial magnetic stimulation OR transcranial alternating current stimulation)) AND ((perspective OR perspectives) OR (opinion OR opinions) OR (view OR views) OR (interview OR interviews) OR qualitative)

Of these 34 datasets, 14 (41%) had at least one associated publication addressing actual or expected cognitive effects. Only cognitive effects were analyzed.

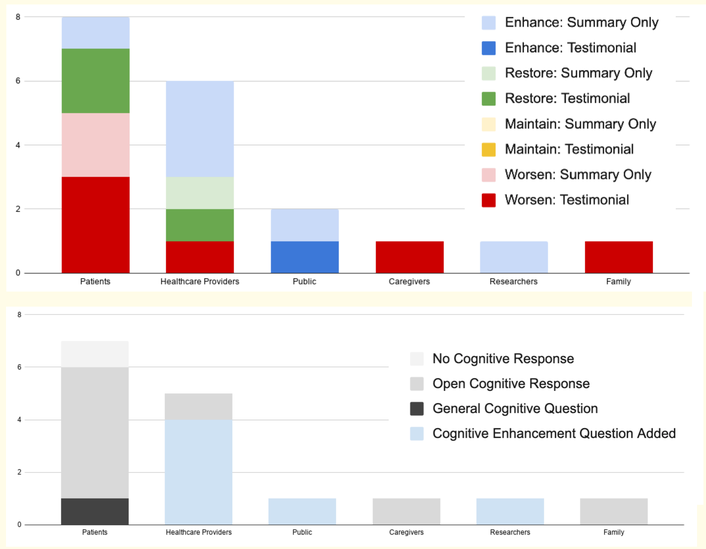

Figure 2. Reported cognitive effects of brain stimulaiton by stakeholder (Top) Patients and healthcare providers most commonly report cognitive effects. (Bottom) Heathcare providers are most commonly asked about cognitive effects—particularly cognitive enhancement.

Quotes on Deep Brain Stimulation (DBS)

Patient with Parkinson’s Disease (Sperens et al., 2017)
Expected Effect | Worsen Cognition (Testimonial) | No Cognitive Question

“Mr. 1 described his fascination about the capacity of the brain and at the same time his fear of being damaged during surgery: ‘I remember a fishing tour, it is twenty-five years ago, I can spot it in a split second…’ and he continued ‘they (the electrodes) are very close to the memory centre.’ ”

Patient with Obsessive Compulsive Disorder (de Haan et al., 2015)
Actual Effect | Restore Cognition (Testimonial) | General Cognitive Question

“ ‘Yes, I can pay attention somewhat better, so to say. Having conversations more easily, or yes, at school that it goes better. Somewhat better at focussing on the task at hand, or at the music [while playing in a band]. Or just watch a comedy for half an hour, say. Because normally I always used to go to the toilet; to the toilet, or washing my hands. Or I got so distracted with my thoughts and then I could not follow the story anymore, for example. So that has improved.’ (11)”

Healthcare Providers (Lipsman et al., 2011)
Expected Effect | Enhance Cognition (Summary) | Cognitive Enhancement Question

“When asked whether it would be ethical to provide surgical memory enhancement to a patient should they request it, 48.6% of respondents (36/74) said it would not be ethical.”

Main Results

Data Collection

Patient-reported cognitive effects or expectations were identified in 7 (50%) of the 14 datasets. Only 1 (14%) of these datasets was sourced by asking patients about cognitive effects. Provider-reported cognitive effects were identified in 5 (36%) of the 14 datasets. 4 (80%) of these datasets asked providers about expectations/experiences related to cognitive enhancement (Fig. 2).

Indicated Treatment Effect

In the studies reviewed, clinicians commented with equal frequency on the possibility of brain stimulation worsening, restoring, or improving cognition, whereas patients (primarily treated for Parkinson’s disease) were more likely to comment on negative effects on cognition.

Discussion

Our findings suggest that previous qualitative literature on brain stimulation lacks focused attention to patient perspectives on actual and expected cognitive effects.

On the one hand, a current reliance on healthcare provider perspectives contributes to underreported cognitive impairment experienced by patients. Without a knowledge of such unintended impairments, clinicians and engineers are unable to respond to the needs of their patients and end-users.

On the other hand, the possibility of future cognitive enhancement was rarely discussed with patients. As such, there remains a lack of knowledge regarding patient expectations of neurotechnologies that seek to go beyond functional restoration. Gathering patient expectations about future devices would enable responsible development in the present—and allow for further responsiveness to the hopes and needs of device users.

Next Steps

As a whole, future studies of neurostimulation should aim to more consistently and rigorously evaluate patient perspectives on potential cognitive effects, both experienced cognitive impairment and expectations about enhancive technologies. Researchers and clinicians involved in existing studies may also benefit from development of qualitative tools that assess cognitive effects on device users.

2020 Annual Meeting of the International Neuroethics Society
October 22-23, 2020 | Online