

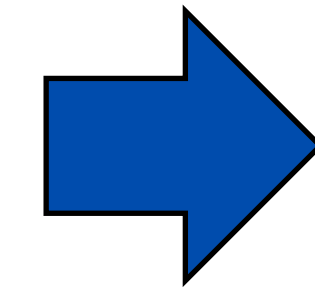
Researchers' perspectives on changes in personality, mood, and behavior in adaptive deep brain stimulation trials

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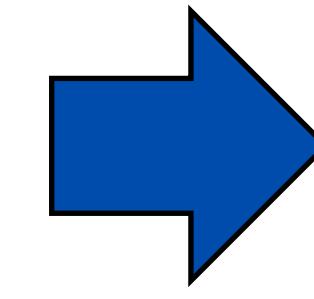
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BACKGROUND

In the neuroethics literature on deep brain stimulation (DBS) and adaptive DBS (aDBS), it is widely claimed that these technologies may cause **changes in personality** [1].



Researchers working with DBS and aDBS likely have **conceptual and ethical views** about this issue that are informed by scientific details of the technologies and interactions with patient-participants [2].



Next-generation DBS researchers are thus a **key stakeholder group** whose perspectives offer important insights on this technology's effect on personality and ethical implications of such effects.

METHODS



We conducted semi-structured interviews with researchers (n = 23) working on next-generation DBS systems. These interviews were audio-recorded, transcribed, and analyzed utilizing MAXQDA software. Five members of the research team collaboratively developed a code book. We employed thematic content analysis to identify and refine themes. Our interview guide included specific questions about personality, including: "Based on your experiences, or experiences that patient-participants or caregivers have shared, have **you noticed any effects that DBS or aDBS has had on patient-participants' personality or behavior?**" We also identified relevant quotes from other parts of the interviews.



RESULTS

Defining "Personality"

"[T]he word personality is thrown around as sort of a general term. I **don't know how scientific that is**, maybe it is scientific maybe it's not. I'm not a psychiatrist, **but definitely changes in mood, in neurobehavior, in impulsivity.**"

"I'd call it **behavior**. I'm happy to call it that. But you asking about changes in personality is totally legitimate because that was a huge issue from the lobotomy era."

Frequency of Changes in Personality, Mood, and Behavior in DBS/aDBS

"Well, first of all I would say it's **rare**."

"Yeah, I wouldn't say they're common, but we have seen them **in a small number of patients**."

"Certainly **at least half** the cases [of obsessive-compulsive disorder]."

"They can be **fairly common** depending on the target that you use [for Parkinson's disease]."

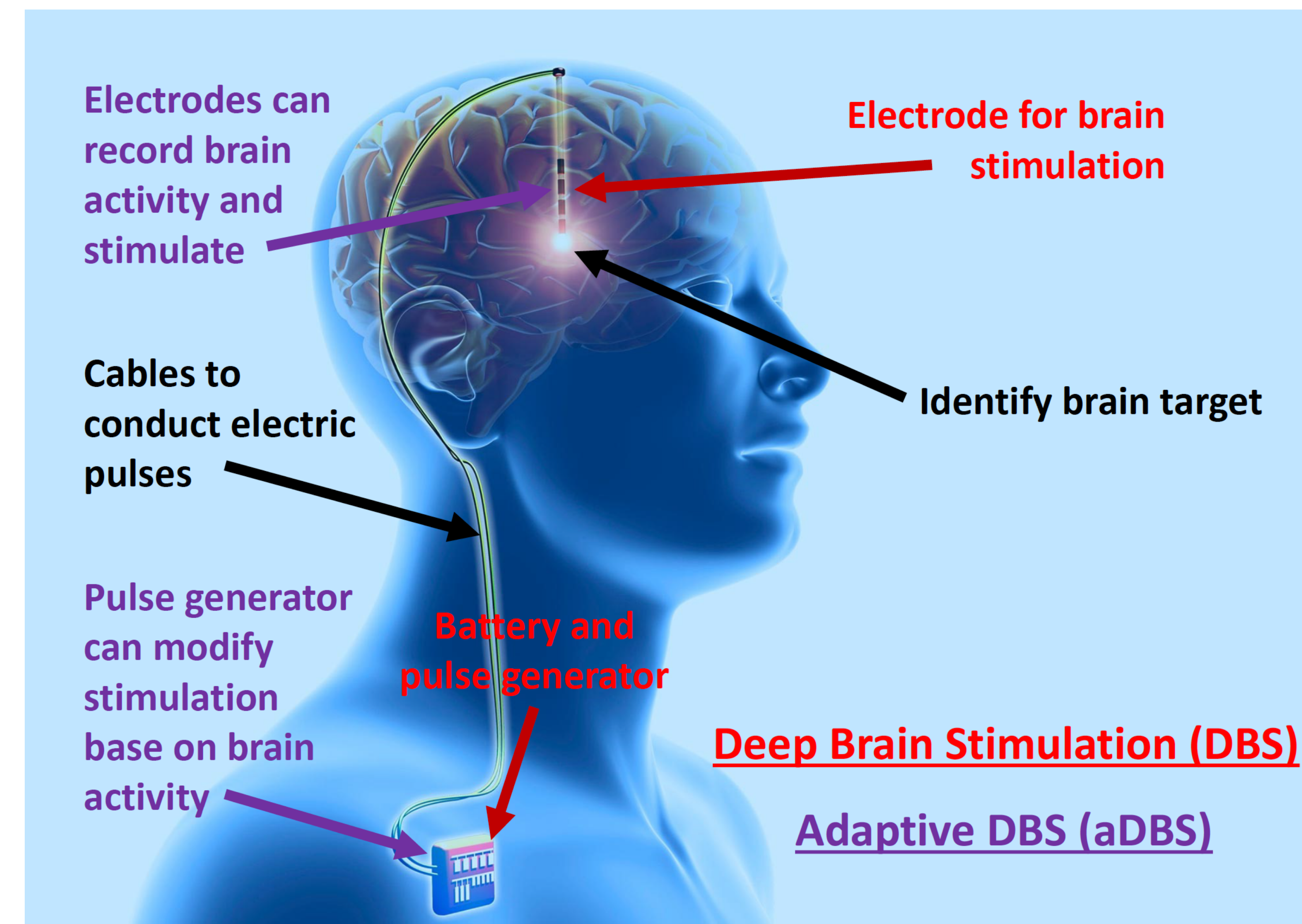
Types of Change

"We have seen impulsivity, or an **increase in impulsivity** associated with stimulation, and worsening depression."

"[W]ith DBS, even without the adaptive component, there's a possibility of inducing **personality changes, impulsiveness, cognitive changes and other issues**."

"[W]ith subthalamic nucleus stimulation... you can also see people having a depressed mood or just being more emotional. **Having more emotional expression but not really feeling a connection with that feeling itself** but having the reaction that you do, but not really feeling the same way."

"There are, with conventional DBS, we've had patients where stimulation can produce some **personality changes, greater impulsivity, manic-type behavior**. Often those are exacerbations of a pre-existing tendency. That is not uncommon in Parkinson's disease with conventional DBS."



High-level features of DBS and aDBS

Other Potential Causes of Change

"But we also see that in regular Parkinson's and many of these basal ganglia diseases, so is it **always the stim?**"

"There may be **other reasons that those changes happen**, but it's in the context of delivering that therapy, so things like medication adjustments or medication changes or concurrent illness or just progression of disease."

"No, I think if there are any changes, it's **whether the therapy has been effective or not**."

"I think the changes could be secondary to **any sort of brain surgery**."

Change as a Therapeutic Goal in Psychiatric DBS/aDBS

"[...]the OCD and depression cases I've been involved with, there **we're officially trying to manipulate emotions and moods and such**."

"[W]hen you're talking about psychiatric DBS in terms of DBS for that, then **obviously we're looking for a behavior change because there's pathologic behaviors**, so that's the intended effect."

"So, it's **tricky because in a sense we do want to change some of the personality for the better**, and that's kind of what we're trying to shoot for. The difficult part is making sure that we don't change anything for the worse."

"[T]he goal of deep brain stimulation in an OCD patient is to **change their behavior**. So it's sort of part of the point in this particular case. Very different from essential tremor, for example."

Role of Patients in Determining Acceptability of Changes

"I **would defer it to the patient themselves** to decide what was a positive change or it was worth it or it was not."

"I think we would also want to make sure that a patient is going to be comfortable with the parameters that we're operating under and that it is **not something that's making them feel like their personality is changing to an area where they're not themselves anymore**."

"And let's say we send, you know, the stimulation sends the patient into a manic or hypomanic state where they feel too happy to the point where it's like destructive for them. **Would they be able to admit that and see that it's not good for their functioning? Is it fair for us to tell them that that's not the way to live?**"

Future Research Directions

"We **don't do, as far as I'm aware, any personality testing**. We do neuropsychological executive function testing, memory testing, cognitive testing. We don't do personality testing."

"[E]specially on the mood side of things, **how do we measure what we're doing[...]**?"

CONCLUSION

Researchers expressed different views of the **frequency** of changes in personality in DBS and aDBS. This variation is potentially explained by researchers holding different views of what **counts** as a change in personality rather than a change in mood and behavior only. Further research is needed to determine the extent of **definitional variation** in how researchers understand personality and related concepts, as these definitions have methodological implications for how to operationalize personality for empirical measurement. Further research is also needed to assess how researchers assess the **desirability** of changes in personality, mood, and behavior and the role of **patients' own viewpoints** in these assessments. Finally, the fact that change is a therapeutic goal of DBS/aDBS for some psychiatric disorders suggests that **future work in neuroethics may need to distinguish more sharply between motor and psychiatric uses of DBS and aDBS**.

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[1] Gilbert F, Viaña JNM, Ineichen C. (2018). Deflating the "DBS causes personality changes" bubble. *Neuroethics*. <https://doi.org/10.1007/s12152-018-9373-8>.

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