

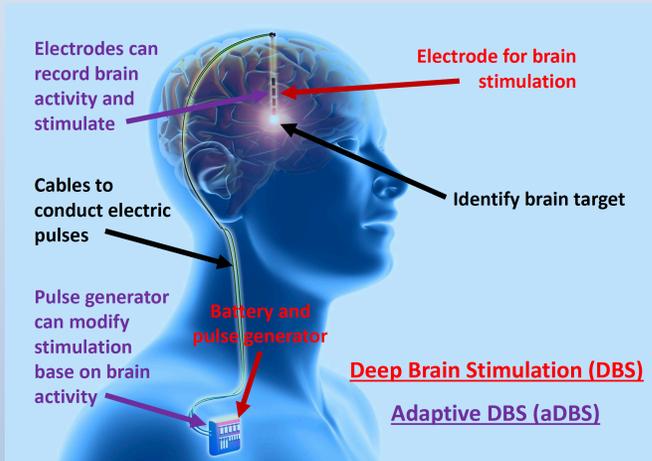
Participant Perspectives on Personality, Identity, Mood, and Behavioral Changes in Experimental Deep Brain Stimulation

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Background

The scientific and neuroethics literature has emphasized the possibility of changes in personality, identity, mood, and behavior (PIMB) among recipients of deep brain stimulation (DBS).

- Frequency, character, and magnitude of PIMB changes are unresolved.
- Participant perspectives provide important qualitative evidence about PIMB changes.



Methods

- We interviewed **participants in experimental DBS research (n=21)** pre- and 6 months post-surgery. Participants were receiving experimental DBS for Parkinson's disease (n=8), obsessive-compulsive disorder (n=5), Tourette syndrome (n=4), essential tremor (n=3), and dystonia (n=1).
- Participants were asked what effect DBS had on their behavior or personality, whether it changed them as a person, and whether it impacted the degree to which they feel authentically themselves.
- Transcripts were analyzed using **thematic content analysis**.

Results

Valence of PIMB effects

- Only positive PIMB effects (n=12)
- Only negative PIMB effects (n=1)
- Both positive and negative (n=6)
- No PIMB effects (n=2)

Positive PIMB effects (n=18)

- Improved sociality/relationships (n=13)
- Relaxed/less anxious (n=8)
- Greater confidence/agency (n=7)
- Happier (n=6)
- Sense of meaning/optimism (n=5)
- Openness to world/others (n=3)
- More "present" (n=2)

Negative PIMB effects (n=6)

Unwanted emotionality (n=2)

"I can be way more emotional, but I don't think that's related to the device. I think that's related to PD because I remember discussing that with a psychologist prior to surgery. Now, it may have increased."

"It's something with my emotions and I can't stop them. I literally cannot stop. I mean, I cry. I even try not to cry and I just can't."*

Temporary post-surgery cognitive issues (n=2)

"It was probably a week after surgery I guess, at least a week. And I got to where I actually shut down. I wouldn't speak. I just would sit for hours and hours and not speak unless I was spoken to because I was almost embarrassed that I was struggling getting words out and stuff like that. But that since just went away."*
[*Same participant]

"The first 10 days after the surgery I was a completely different person and my husband said, 'I'm getting worried about you,' but then I snapped back to my old self. I was depressed and I don't know, just morose, but I snapped out of that after 10 days."

Adjustment to new stimulation parameters (n=1)

"[When] they decide to turn it up, leave it the same, or turn it down, it can be kind of wackadoodle there in the middle [...] the first time [a researcher] turned it up I was definitely, for the next few days, I just wouldn't shut [...] up."

Diminished energy (n=1), slightly increased anxiety (n=1)

Post-surgery sense of identity

"New" sense of identity (n=1)

"Every time I go and get reprogrammed, there's another new me."

Returned to pre-disorder sense of identity (n=8)

"I'm just going back to the way, who I was before. Because Parkinson's changed me. I'm feeling like I'm coming out of it now."

"This may sound weird, but I feel like I'm more me than I've ever been in my life."

Same as before DBS (n=11)

"I think I have the same personality, but just happier."

Unsure (n=1)

Conclusions

- ❑ **Negative PIMB-related impacts were few in number but notable in character and magnitude.**
- ❑ Most participants described **positive PIMB changes**.
- ❑ These findings raise questions about how to conceptualize the **relationship between disorders, DBS, and PIMB**.

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