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

<table>
<thead>
<tr>
<th>Valence of PIMB effects</th>
<th>Negative PIMB effects (n=6)</th>
<th>Post-surgery sense of identity</th>
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<tbody>
<tr>
<td>Only positive PIMB effects (n=12)</td>
<td>Unwanted emotionality (n=2)</td>
<td>“New” sense of identity (n=1)</td>
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<td>Only negative PIMB effects (n=3)</td>
<td>“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.”*</td>
<td>“Every time I go and get reprogrammed, there’s another new me.”</td>
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<td>Both positive and negative (n=6)</td>
<td>“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.”**</td>
<td>Returned to pre-disorder sense of identity (n=8)</td>
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<td>No PIMB effects (n=2)</td>
<td>Temporary post-surgery cognitive issues (n=2)</td>
<td>“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.”</td>
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Positive PIMB effects (n=18)
| Improved sociality/relationships (n=13) | “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.”** | “This may sound weird, but I feel like I’m more me than I’ve ever been in my life.” |
| Relaxed/less anxious (n=8) | “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.” | Same as before DBS (n=11) |
| Greater confidence/agency (n=7) | Adjustment to new stimulation parameters (n=1) | “I think I have the same personality, but just happier.” |
| Happier (n=6) | “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 [...].” | Unsure (n=1) |
| Sense of meaning/optimism (n=5) | | |
| Openness to world/others (n=3) | Diminished energy (n=1), slightly increased anxiety (n=1) | |
| More “present” (n=2) | | |

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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