Title

Participant perceptions of changes in psychosocial domains following participation in an adaptive deep brain stimulation trial.

Permalink

https://escholarship.org/uc/item/9db9v00d

Journal

Brain Stimulation, 16(4)

Authors

Merner, Amanda
Kostick-Quenet, Kristin
Campbell, Tiffany
et al.

Publication Date

2023

DOI

10.1016/j.brs.2023.06.007

Copyright Information

Published in final edited form as:
Brain Stimul. 2023 ; 16(4): 990–998. doi:10.1016/j.brs.2023.06.007.

Participant perceptions of changes in psychosocial domains following participation in an adaptive deep brain stimulation trial

Amanda R. Merner[a], **Kristin Kostick-Quenet**[b], **Tiffany A. Campbell**[a], **Michelle T. Pham**[c], **Clarissa E. Sanchez**[b], **Laura Torgerson**[b], **Jill Robinson**[b], **Stacey Pereira**[b], **Simon Outram**[d], **Barbara A. Koenig**[d], **Philip A. Starr**[e], **Aysegul Gunduz**[f,g], **Kelly D. Foote**[f], **Michael S. Okun**[f], **Wayne Goodman**[h], **Amy L. McGuire**[b], **Peter Zuk**[a], **Gabriel Lázaro-Muñoz**[a,i,*]

[a]Center for Bioethics, Harvard Medical School, 641 Huntington Avenue, Boston, MA, 02115, United States

[b]Center for Medical Ethics and Health Policy, Baylor College of Medicine, One Baylor Plaza, Suite 326D, Houston, TX, 77030, United States

[c]Center for Bioethics and Social Justice, Michigan State University, East Fee Hall, 965 Wilson Road Rm A-126, East Lansing, MI, 48824, United States

[d]Program in Bioethics, University of California, San Francisco, 490 Illinois Street, San Francisco, CA, 94143, United States

[e]Department of Neurological Surgery, University of California, San Francisco, 400 Parnassus Avenue, San Francisco, CA, 94143, United States

[f]Norman Fixel Institute for Neurological Diseases, Departments of Neurology and Neurosurgery, University of Florida, 3009 SW Williston Road, Gainesville, FL, 32608, United States

---

[*] Correspondence: Gabriel Lázaro-Muñoz, glazaro@hms.harvard.edu.

Declaration of interest: None.

CRediT author statement:
Amanda R. Merner: Conceptualization, Methodology, Validation, Formal analysis, Visualization, Writing – original draft, Writing – review & editing
Kristin Kostick-Quenet: Methodology, Writing – review & editing, Visualization
Tiffany A. Campbell: Formal analysis, Writing – original draft, Writing – review & editing
Michelle T. Pham: Formal analysis, Writing – review & editing.
Clarissa E. Sanchez: Formal analysis, Writing – review & editing, Data curation.
Laura Torgerson: Investigation, Data curation, Writing – review & editing, Project administration
Jill Robinson: Writing – review & editing
Stacey Pereira: Stacey Pereira: Methodology, Writing – review & editing.
Simon Outram: Simon Outram: Investigation, Writing – review & editing.
Barbara A. Koenig: Methodology, Investigation, Writing – review & editing
Philip A. Starr: Resources, Writing – review & editing
Aysegul Gunduz: Resources, Writing – review & editing
Kelly D. Foote: Resources, Writing – review & editing.
Michael S. Okun: Resources, Writing – review & editing.
Wayne Goodman: Conceptualization, Methodology, Resources, Writing – review & editing, Supervision, Project administration, Funding acquisition
Amy L. McGuire: Conceptualization, Methodology, Writing – review & editing, Supervision, Project administration, Funding acquisition.
Peter Zuk: Conceptualization, Methodology, Formal analysis, Investigation, Data curation, Writing – original draft, Writing – review & editing, Project administration.
Gabriel Lázaro-Muñoz: Conceptualization, Methodology, Validation, Formal analysis, Investigation, Writing – original draft, Supervision, Writing – review & editing, Project administration, Funding acquisition.

[g]Department of Biomedical Engineering, University of Florida, 1275 Center Drive, Biomedical Science Building, JG283, Gainesville, FL, 32611, United States

[h]Department of Psychiatry and Behavioral Sciences, Baylor College of Medicine, 1977 Butler Blvd Suite E4.100, Houston, TX, 77030, United States

[i]Department of Psychiatry, Massachusetts General Hospital, 55 Fruit Street, Boston, MA, 02114, United States

Abstract

Background: There has been substantial controversy in the neuroethics literature regarding the extent to which deep brain stimulation (DBS) impacts dimensions of personality, mood, and behavior.

Objective/Hypothesis: Despite extensive debate in the theoretical literature, there remains a paucity of empirical data available to support or refute claims related to the psychosocial changes following DBS.

Methods: A mixed-methods approach was used to examine the perspectives of patients who underwent DBS regarding changes to their personality, authenticity, autonomy, risk-taking, and overall quality of life.

Results: Patients (n = 21) who were enrolled in adaptive DBS trials for Parkinson’s disease, essential tremor, obsessive-compulsive disorder, Tourette’s syndrome, or dystonia participated. Qualitative data revealed that participants, in general, reported positive experiences with alterations in what was described as ‘personality, mood, and behavior changes.’ The majority of participants reported increases in quality of life. No participants reported ‘regretting the decision to undergo DBS.’

Conclusion(s): The findings from this patient sample do not support the narrative that DBS results in substantial adverse changes to dimensions of personality, mood, and behavior. Changes reported as “negative” or “undesired” were few in number, and transient in nature.

Keywords

neuroethics; neurotechnology; ethics; deep brain stimulation; neuromodulation; personality

Introduction

Deep brain stimulation (DBS) is considered a safe and effective intervention for appropriately selected patients with movement disorders, including Parkinson’s disease (PD) [1], essential tremor (ET) [2], dystonia (DYS) [3], and severe epilepsy [4]. Research has expanded for other indications, including treatment-refractory psychiatric disorders such as obsessive-compulsive disorder (OCD) [5] and Tourette’s syndrome (TS) [6], among others. Although the safety and efficacy of DBS for movement disorders have been well established, concerns have emerged regarding the potential for DBS to result in ‘undesirable’ changes in dimensions of personality, identity, agency, authenticity, autonomy, and self (PIAAAS) [7–11].

Despite this narrative within the neuroethics literature regarding changes to PIAAAS, Gilbert and colleagues have argued that there is insufficient empirical data to support or refute claims regarding these purported changes, and they and others have suggested that the theoretical concerns exceed the current empirical research available on this topic [7, 12–13]. Further, the limited published data that do exist exploring PIAAAS changes—and alterations to personality, mood, and behavior broadly—have been mixed.

Some studies report participants experiencing no significant changes in PIAAAS dimensions following DBS [14–19], or only changes that resolve quickly. For example, in patients with OCD, many who report post-surgical anxiety also reported that it diminished once optimal stimulation parameters were identified [20], and some who reported changes in mood also stated that they experienced these mood fluctuations before surgery, so this was not necessarily a result of stimulation [20].

Several studies have presented findings of positive changes following DBS. For example, some researchers have reported restorative personality effects of DBS for patients with PD when patients were asked about changes to their most valued personality traits [13]. Others have reported decreases in anxiety and depression in patients with PD [21]. Positive changes in patients' sense of global life control have also been reported in PD patients following DBS, with participants highlighting their increased independence and positive outlook on life, and diminished feelings of fear or anxiety related to their physical limitations [22]. In those with OCD, several studies have presented findings from participants who also report feeling more themselves and less anxious after DBS, indicating a shift toward more positive emotionality, which is an intended outcome of DBS for OCD [23–25].

Other researchers have reported negative or undesirable changes after DBS [9, 10, 23, 24, 26, 27]. Some have observed that despite positive surgical outcomes and increased symptom control, participants find it difficult to return to their lives and adjust socially [9, 10, 26]. For some, this may be characterized as increased apathy, which is a side effect that has been reported [27], and in DBS patients with PD, has been at least partially attributed to titration of dopaminergic medications post-DBS [28]. At the other end of the motivational spectrum, there is also literature describing the development, or exacerbation of impulse control disorders in PD patients who underwent DBS (e.g., problematic gambling, hypersexuality, increased substance use) with incidence rates ranging between 1% and 15% [10, 29]. Feelings of unwanted hypersexuality, as well as increased irritability, have also been reported in individuals who received DBS for treatment of OCD [23, 24]. Finally, hypomania has been reported as a less common effect in both DBS for PD [30] and OCD [20, 31].

As we and others have described elsewhere, these changes are not necessarily directly due to stimulation [12, 32, 33]. Although some changes (e.g., mood, impulsivity, acute hypomania) may be more directly related to stimulation affecting neurophysiological processes, there are several other potential causes. For example, patients may experience feelings of decreased authenticity due to being unsure whether their mood and behaviors are theirs, or are instead being controlled by the DBS device. The sudden relief from severe symptoms related to one's disorder can also influence dimensions of PIAAAS. Relationships with family members and care partners may change in both positive and negative ways as both groups navigate their new normal and roles evolve.

However, it’s important to note that much of the research in this area—particularly the qualitative research—has relied on only post-surgical interviews or retrospective data, rather than data that has been collected prospectively, which can provide an informative baseline to reference when exploring post-operative changes. Given the growing interest in expanding the use of DBS beyond movement disorders into other patient populations—particularly treatment-refractory neuropsychiatric disorders in which changes to personality, mood states, and behaviors may be a desired treatment outcome, we believe it will be critical to gather as much empirical data as possible from DBS patients that can speak to whether or not DBS might produce meaningful changes in dimensions of PIAAAS. Further, if patients are experiencing such changes as a result of DBS, it will be important to characterize the frequency, magnitude, and valence of these changes in order to ensure future patients are fully informed about the potential for DBS to impact them [12]. Understanding these phenomena will also provide insight into patients’ perspectives surrounding whether or not such changes might outweigh the therapeutic benefits of DBS.

The current study used a mixed-methods approach to empirically explore changes in domains commonly discussed in the neuroethics literature, including personality, authenticity and autonomy, and risk-taking behaviors from the viewpoint of the patient-participants. Changes in quality of life and decisional regret were assessed, and insights were sought into participants’ experiences of benefits and harms when undergoing DBS for a diverse set of disorders.

Material and Methods

Participants

Participants were recruited from five different adaptive DBS (aDBS) clinical trials in the United States. Upon enrolling in one of the partnering aDBS trials, participants were informed about the potential for participating in the current study. Interested individuals were contacted by a member of the research team and those who decided to participate provided informed consent. Most patients agreed to participate (response rate 91.3%, or 21/23). All study procedures were approved by the Baylor College of Medicine Institutional Review Board.

Measures

Each participant completed an in-depth, semi-structured interview and a brief battery of questionnaires prior to DBS or activation of the device and approximately six-months after surgery. Semi-structured interviews to assess changes in personality, authenticity and autonomy, risk-taking, quality of life, and regret associated with the decision to undergo DBS were developed based on a review of the literature, discussions with DBS researchers, and preliminary qualitative data from researchers. The questions asked were in relation to changes participants experienced after DBS generally, as each of the aDBS trials was at different stages of development in regards to the adaptive function. Participants were also asked about concerns they may have regarding adaptive functions that may relate to questions of changes in PIAAAS (e.g., adaptive stimulation impacting autonomy). The main focus of this paper is on the qualitative findings; additional information regarding the quantitative self-report measures can be found in the Supplementary Materials.

Analyses

Qualitative Analyses—All interviews were audio recorded and later transcribed. Transcripts were analyzed using MAXQDA 2018 [34]. Based on a review of clinical and ethical issues discussed in the literature around DBS, the research team created a preliminary codebook that was used to identify excerpts of text in transcripts that described potential changes related to personality, authenticity, autonomy, risk-taking, quality of life, and regret. Other codes were inductively added to the codebook by team consensus, based on additional topics and potential themes identified during preliminary rounds of coding. Members of the team used thematic content analysis to iteratively identify themes in the data, with at least two team members coding each transcript to maximize data capture and to reconcile potential differences in interpretation [35][36]. Three rounds of preliminary coding were employed in order to examine similarities in coding applications among coders, with regular meetings to examine coding styles (code applications based on semantic content as well as quotation length) and to reduce variation in coding styles and achieve greater consensus among coders. Preliminary coding rounds also provided information about which coders were most similar versus different, which we used to assign sets of transcripts to pairs of maximally different coders in order to maximize coding coverage (i.e., one coder picked up on what the other may have missed). Likewise, once quotations were exported into code outputs for analysis using iterative phases of abstraction of raw quotes and organized into themes, all themes were corroborated by two members of the research team [36]. The members of the research team primarily involved in the qualitative data analysis process included three researchers with backgrounds in philosophy; one with additional work experience in a neuroengineering center as part of their training (MP), another who was trained in empirical bioethics work throughout the course of conducting this project (PZ), and a third for whom this area of research was novel (TC). The final research team member involved was trained as an experimental psychologist with an extensive background in DBS research (AM). Data from post-DBS interviews are reported here, with pre-DBS interview data drawn upon as needed to contextualize post-surgery responses. Information regarding quantitative analyses can be found in Supplementary Materials.

Results

Twenty-one participants completed semi-structured interviews pre- and post-DBS, and post-operative data are reported. Although the final sample size is sufficient to conduct qualitative analyses [37], it was too limited to provide meaningful statistical comparisons on quantitative measures; however, the exploratory results from the quantitative measures are included in the Supplementary materials for transparency, and to serve as additional information for researchers to use for future hypothesis generation. Detailed participant demographics have been reported previously [38]. Overall, the sample was predominantly white and non-Hispanic, and included individuals with obsessive-compulsive disorder (n=5; target: ventral striatum), Parkinson's disease (n=8; target: subthalamic nucleus), essential tremor (n=3; target: ventral intermediate nucleus), Tourette's syndrome (n=4 target: centromedian thalamic region), and dystonia (n=1; target: subthalamic nucleus). The aDBS trials that our team recruited from were at different stages in the development of the adaptive systems, and therefore some did not receive aDBS by the time the post-operative data were collected.

Personality

A large majority (17/21) of participants described what we interpreted as personality-related benefits of DBS, in which there was a positive shift or return to a pre-disorder state of being, summarized in (Table 1). Over half (14/21) described psychological benefits, which are subdivided into the domains of emotional state, meaningfulness, openness, and greater focus or feeling more "present." Over half (14/21) also described benefits to their interpersonal relationships and/or ability to engage in social activities. Nearly half (10/21) described greater confidence or sense of agency. Due to a high degree of overlap with other themes, we describe those findings in more detail in the sections on Autonomy and Quality of Life below.

Negative personality-related impacts were few in number but notable in character. They included greater emotionality, acute but temporary post-surgical effects, talkativeness following stimulation adjustments, and increased anxiety (Table 2).

Authenticity

Of the 21 participants, 10 described a change in their sense of identity in the post-surgery interview. One reported a new sense of identity, saying that DBS "has reduced [self-consciousness about my symptoms] quite a bit. And so I'm just getting used to the new me. Every time I go and get reprogrammed, there's another new me." (DYS1). Six (3 with PD, 3 with OCD) reported having returned to a *pre-disorder* sense of identity, and two additional participants (1 with PD, 1 with OCD) described being in the process of returning to a pre-disorder sense of identity (Table 3). One additional participant reported an evolving sense of identity, saying "I used to be a lot more motivated in business, and much more energy. Now I take stuff more easy [sic]" (PD4), but did not relate this to their pre-disorder identity, and was unsure whether to attribute this change to aging or to the device.

Notably, seven of these 10 participants (6 who reported returning or being in the process of returning to a pre-disorder sense of identity, and the one participant who reported a new sense of identity) said that their disorder had previously interfered with the full expression of aspects of themselves.

Eleven participants, by contrast, did not perceive any apparent change in sense of identity. One participant, for example, said, "I think I have the same personality, but just happier." Notably, one participant with TS did report their parent saying "It's like you're not the same person" in a positive sense, with reference to beneficial reduction in their tics (TS1). The remaining participant reported that (positive) personality changes had occurred but was unsure if this amounted to a change in her as a person, and also reported lacking a pre-OCD identity to which to return.

Autonomy

Nearly all (18/21) participants described **autonomy-related benefits**, with several describing marked increases in their autonomy in various domains compared to before DBS (see Table 4). Several participants (4/21) reported a new or restored sense of **self-confidence**. Several participants (9/21) described greater ability to engage in **activities of daily living**, with some emphasizing that being able to engage in such activities, which may be taken for granted by people without these disorders, was very meaningful for them. Some participants (6/21) also described **greater freedom** or more of a choice about the course of their lives. A few (3/21) participants also described **greater independence** from others.

Several participants also voiced **autonomy-related concerns** (see Table 5). One participant with PD described needing to be more physically careful so as not to damage the device. A participant with OCD described feeling dependent on the stimulation for anxiety management. A participant with TS described feeling “more run down” due to stimulation, though typically only in the morning. Two participants (one with PD, and another with ET) described balance issues. The latter participant with ET (ET2) also reported some additional physical symptoms that didn’t exist before DBS or were exacerbated by DBS, including issues with speech and movement (i.e., slight dragging of their right foot). The participant also reported that thinking about or turning their attention to their hands would activate the stimulation, an unexpected issue with the adaptive system that the clinical trial team was working to resolve. This participant also described experiencing transient adverse events during implantation surgery and a subsequent study visit in which stimulation was briefly turned up “high enough to where it makes me feel like I had a stroke. And I mean, literally a stroke. I lost total control of my body” (ET2). The participant interpreted the episode during surgery as a test and the episode during a study visit as a mistaken change to the stimulation parameters. This participant did not attribute any of the issues they experienced with respect to speech, movement, hands, transient post-surgery effects, or unwanted emotionality (see Table 2) to these episodes, and they reported being assured by the clinical team that the stimulation could never reach a level that would result in permanent damage.

One autonomy-related concern about how the automatic, adaptive changes to stimulation may lead to people feeling as though they are a ‘robot’ is often discussed in the aDBS literature; however, it did not present itself in any of the interviews. When asked, “The adaptive DBS device automatically changes the stimulation it delivers to your brain based on the measurements it takes of your brain activity. How do you feel about this?”, 17/21 participants expressed no concerns with the adaptive stimulation. The remaining 4/21 were characterized as ambivalent because they indicated that although they weren’t concerned about the adaptive function they would still want some control over the stimulator (ON/OFF function) in case of any sudden negative side effects (2/21), or they felt they weren’t good candidates for the adaptive protocol due to their personal reactions to stimulation changes (2/21). Outside of the question specific to whether or not they were concerned about the automatic changes in stimulation, one participant told a story in which he jokingly described himself as a “cyborg” when asked about his DBS device at an airport. However, this comment was made in a positive, joking manner, and when asked about whether or not they were concerned with the adaptive stimulation the participant had no concerns and expressed looking forward to being one of the first people to have the adaptive system.

Risk-Taking Propensity

When asked to discuss risk-taking behavior, nearly all participants (16/21) responded with a clear negative answer to our question about whether DBS had impacted their **propensity to take risks**. Some of the patients receiving DBS for OCD clarified that while DBS had not increased *problematic* risk-taking, it had increased their ability to take *desirable* risks. For example, one participant said:

> "I do think I'm able to take a little more of the risks that I would have taken pre-OCD getting really bad…So I don't consider that a change in my risk-taking ability, but it is a change from what it was right before the surgery, but it's not a change in my risk-taking as a person." (OCD1)

Another participant described being able to ride rollercoasters again as a desirable risk to which DBS would hopefully enable him to return. Additionally, one participant with TS described themselves as someone who takes risks, but it was unclear whether they attributed this to the device.

Quality of Life

We identified four principal domains in which participants experienced positive changes in quality of life, including 1) physical status and functional abilities, 2) psychological status and well-being, 3) autonomy, and 4) interpersonal relationships.

Within the domain of **physical status and functional abilities**, participants discussed multiple areas of improvement, particularly **symptom reduction** and ability to **reduce medications** (see Table 6). Symptom reduction and titration of medications increased many participants' ability to accomplish everyday tasks such as working at a job, doing household chores and running errands, and caring for one's personal hygiene, which was noted by most (18/21) participants as an important outcome for their improved quality of life.

Participants also discussed improved **psychological status and well-being (18/21)** (see Table 7), particularly in the areas of mood/emotionality, confidence (discussed in the Autonomy-Related Benefits section), greater sense of hopefulness, meaningfulness and purpose (i.e., existential improvement), and cognition. **Improved mood** (14/21) is reported across all condition-types represented in the trial and is frequently and explicitly related to symptom reduction, with the exception of a few patients experiencing unwanted emotionality (Table 2., Personality section). Many participants reported feeling "hopeful," "happy," and "more positive", with regard to their mood, as well as their views on life, denoting **existential improvement (17/21)**. Lastly, some participants (5/21) with OCD or PD described **cognitive improvement**, including clearer thinking (e.g., less "brain fog" or increased focus) and decreased rigid thinking, including being more open to experience (i.e., "open-minded"). However, one participant noted feeling cognitively slower after undergoing DBS.

Finally, many participants (10/21) reported improvement in the domain of **interpersonal relationships** (see Table 7). Some of these participants stated they were able to be more “helpful” or “useful” in completing household errands or chores, which in turn helped their familial relationships. Many participants said that DBS has enabled them to socialize more with friends and family; decreased symptomology was related to increased participation in activities that prior to DBS were difficult, increased social confidence, increased desire for sociality or engagement in relationships, as well as decreased need to be homebound.

Overall, almost all participants (18/21) reported improvement or significant/major improvement in their quality of life, with the remainder reporting some improvement or no change pre-DBS to post-DBS. Participants’ descriptions of their remaining challenges or lack of change to quality of life are reported in Table 8.

Regret

Overall, participants unanimously expressed that they did not regret undergoing DBS for treatment of their respective disorders. When asked if they had any regrets about their decision to have their DBS device implanted, one participant responded, “I don’t have any regrets at all. It was one of the better decisions I’ve ever made.” (ET3) Another participant felt it gave them a second chance in life, “Yeah, zero regrets. I honestly don’t know how I could have kept going on, the way it was pre-surgery. So, I’m just incredibly grateful to have a shot back at life again.” (OCD1) And several explicitly stated if they were faced with the decision to undergo DBS again, that they would do so, and would recommend it to friends or others in similar circumstances.

Discussion:

This study examined changes in dimensions of personality, authenticity, autonomy, risk-taking, quality of life, and decisional regret in individuals who participated in aDBS trials for management of a treatment-refractory condition. We have characterized the frequency, magnitude, and valence of changes experienced by those who underwent DBS, explored any feelings of regret surrounding their choice to receive DBS, and gathered perspectives regarding the impact of DBS on quality of life. Overall, these results provide additional empirical information from the perspectives of patients to inform discussion about the impact of DBS on PIAAAS.

Some neuroethics literature has argued that DBS has negative impacts on aspects of PIAAAS, which is thought to cause significant patient distress or result in changes to identity that induce feelings of self-estrangement [8–10]. However, overall, our data largely stand in contrast to this narrative. The majority of participant interviews suggested declines in neuroticism, or negative affect, and this was regarded as an overwhelmingly positive change among participants, with several reporting that they felt happier, less anxious, more present, and better able to engage in their interpersonal relationships in a positive manner.

A minority of participants did express some negative experiences in dimensions of personality post-DBS, including increased or unwanted emotionality, increased anxiety, and temporary post-surgical effects or changes immediately following adjustments to stimulation parameters. However, the reported temporary post-surgical and stimulation adjustment-related effects were resolved. Further, the participant with PD who reported increased anxiety was not sure whether it was the result of stimulation or simply the continued progression of their disorder, and stated they felt the latter more responsible. Similarly, one of the participants reporting greater emotionality attributed this to disease progression rather than DBS participation. This highlights an important question that is present in several of the participants' interview responses: To what extent are some of the changes that participants report experiencing directly attributable to the device or stimulation? Although the introduction of an implantable neural device and stimulation certainly can induce changes—particularly given electrode placement and proximity to neural networks that influence emotion or aspects of personality—it's important to emphasize that individuals do not receive DBS in a vacuum. Rather, there are changes occurring at the biological, psychological, and social levels that can interact to prompt alterations in personality, mood, or behavior. Some of the potential alternative causes of change have also been discussed in interviews with researchers who have been involved in developing DBS devices [11].

For example, once patients begin receiving stimulation, they often undergo some degree of titration of their medications, which can impact cognitive and affective processes and impact behavior [28]. Individuals with neuropsychiatric disorders that have a neurodegenerative course (e.g., Parkinson's disease) may also continue to experience changes due to disease progression, as noted by two of the participants. Interpersonal relationships can undergo complex transformations as patients and care partners adjust to their restored or changing abilities and families acclimate to their new roles [39]. And most importantly, these individuals are also typically experiencing marked symptom relief after years of living with severe treatment-refractory conditions, which can alter their lives significantly, with previous work demonstrating DBS patients can experience renewed independence and feelings of increase global control in their lives [22]. Although these biopsychosocial changes may happen alongside surgery and beginning stimulation, they are not necessarily the direct result of the stimulation itself. In fact, a few participants specifically noted in their interviews that they were unsure of whether changes they experienced should be attributed to the device itself. It is important to carefully consider the origins of the changes being reported by patients who receive DBS, as many can be addressed through careful management of medications, adjustment of stimulation parameters, or the addition of psychotherapy during the initial transition periods. These changes are often not permanent, nor do they require deactivating or explanting a device that otherwise provides symptom relief for those with treatment-refractory conditions.

Further, it is important to contextualize some of these experiences within the timeframe that they are being discussed and the timing of the research assessment. Several of the transient negative experiences reported by the participants took place during the first couple of weeks post-surgery, or immediately following changes in stimulation. These experiences may largely represent post-surgical effects and an adjustment period as optimal stimulation parameters are determined and the individual adjusts to the device. These experiences are important to report, as future DBS candidates should be aware of the potential of experiencing some of these transient side effects, but it is also important to clarify that in our sample they did not generally represent lasting changes to dimensions of personality or the self, and they largely resolved themselves within a short period of time.

Another predominant concern in the literature revolves around changes in individuals' sense of identity that are perceived as negative. However, our data largely did not raise this concern. Rather, experiences captured by participant interviews generally reflected either positive changes with respect to identity or a lack of change. Several participants discussed how their disorders negatively interfered with the full expression of their identities and said they were either returning to, or had already returned to a pre-disorder sense of self, which they attributed to DBS. In these participants, DBS appeared to be restorative to participants' overall sense of identity. Others reported no direct changes to their identity, but reported they felt happier, more independent, and confident, which we interpreted to be positive changes. These changes were often spoken about in relation to significant symptom relief brought about by DBS. One participant reported feeling as though each time they were reprogrammed they were a “another new me;” however, the participant seemed to understand this positively. Taken together, our data suggest that DBS can have positive effects on feelings of identity, particularly in those who feel that their disorders are interfering with their authentic selves.

Finally, we acknowledge that it is imperative to not only investigate whether or not there are changes in dimensions of PIAAAS as a result of DBS, but also to explore whether these changes significantly impact individuals' feelings of regret surrounding their decision to undergo DBS or overall quality of life. Gaining insight in these experiences allows us to determine whether the changes in personality or identity are truly meaningful to the participants and can help discern whether those who underwent DBS feel as though the benefits they received from this treatment option outweigh the harms or negative experiences they may have reported. Our data suggest that participants largely felt that the benefits of DBS outweighed the harms or negative experiences. Participant reports on quality of life were overwhelmingly positive, with nearly all participants indicating an improvement in their quality of life. The benefits spanned several domains of functioning, ranging from improved physical functioning and independence with daily activities, to cognitive and affective benefits, to increased hope and feelings of a renewed chance at life. Most participants in this study also reported low levels of regret on the self-report measure (see Supplementary Materials), and unanimously reported not regretting their decision to undergo DBS during their interviews, with several stating emphatically that they would make the same decision again.

Limitations:

We acknowledge that though the sample size is sufficient for conducting qualitative analyses, it is limited. Although this is not uncommon for DBS studies, it highlights the need for future studies to follow up on these topics in a larger sample of participants. While the inclusion of a diverse set of disorders in the study sample is a strength, as it brings varying viewpoints to the semi-structured interviews, it also limits our ability to fully observe the potential influences of disorder type, stimulation target, and other neurobiological variables that can influence these domains.

It is also important to consider the cross-sectional nature of this study, and to recognize these data represent a brief snapshot into the effects of DBS on participants' lives. Future studies should follow-up with participants over a longer period of time to examine the long-term implications of DBS, as participants in this study may still be in an adjustment period post-surgery, which could result in skewed reports depending on whether or not they have adjusted to stimulation or identified the optimal stimulation parameters. Given the previous research demonstrating that patients and care partners may report discordant views on personality, mood, and behavior changes, an additional limitation to our work is that we do not provide care partners' perspectives on these topics and examine the concordance across reports [40,41]. Future work should incorporate care partners' views for a more complete picture of the potential changes experienced after DBS.

As with any self-reported data, there is also the possibility of biases entering into the interview (e.g., social desirability bias of participants) or data analysis processes (e.g., biases of researchers). Participants may respond in a way that is overly positive or agreeable in the presence of members of the research team, essentially reporting how they think the researchers would want them to feel about their surgical outcome and progress (i.e., social desirability bias). This bias was likely mitigated in our study because the research team was an external team and from an institute that was not affiliated with any of the clinical sites. It is also possible for pre-existing biases from the researchers to enter the data analysis process; however, at all points in the data analysis procedure, we implemented steps to decrease potential for any one researcher's views to dominate the analysis in an attempt to reduce biases and ensure no conflicting interpretations were missed.

We also note that although we reached thematic saturation in our qualitative analyses, we cannot claim that the findings from the semi-structured interviews fully encompassed changes in patients who undergo DBS. Although the participants in this study did not report any significant, sustained changes to the dimensions that we explored, our sample size is limited and from a diverse set of disorders with a range of stimulation targets, and these negative effects have variable and rare incidence rates. For example, as previously mentioned, the incidence rate of postoperative impulse control disorders has been reported to range between 1% and 15% [16, 29] for STN-DBS, which only 9/21 participants in this study received. Therefore, it is possible that with a larger sample size we may have found additional cases of unwanted postoperative changes in dimension of PIAAAS.

Finally, there are individual and cultural differences in how people view and define dimensions of PIAAAS, and a larger, and more diverse participant pool may provide responses outside of the range of what we report here.

Conclusion:

DBS is a safe and effective treatment option for many individuals with severe, treatment-refractory conditions, particularly movement disorders. However, given that DBS requires implanting brain electrodes and delivering electrical stimulation to the organ responsible for processes that some, especially those in the Western world, consider fundamental to who we are, it will be critical to understand how DBS may impact aspects of PIAAAS.

This knowledge will enable future patients to more fully appreciate the range of possible outcomes as they consider this treatment option and provide informed consent. These issues should be discussed along with other traditional surgical risks so future DBS candidates can weigh the possibility of changes to personality and identity against the potential for symptom improvement and improved quality of life. Overall, the participants included in this study reported generally positive experiences with respect to alterations in personality, mood, and behavior. Although there were some changes reported as negative, or unwanted in nature, they were relatively few in number, and often were transient in nature. We hope these additional data add to the conversation surrounding changes to PIAAAS in DBS patients, but recognize that more work needs to be done to address this question.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgements:

The authors gratefully acknowledge the assistance of Rebecca Hsu, Lavina Kalwani, Katrina Muñoz, Richa Lavingia, and Arturo Balaguer.

Funding:

This work was supported by a BRAIN Initiative grant from the National Institute of Mental Health of the National Institutes of Health, Award Number R01MH114854.

References

[1]. Volkmann J, Allert N, Voges J, Weiss PH, Freund HJ, & Sturm V (2001). Safety and efficacy of pallidal or subthalamic nucleus stimulation in advanced PD. Neurology, 56(4), 548–551. [PubMed: 11222806]

[2]. Baizabal-Carvallo JF, Kagnoff MN, Jimenez-Shahed J, Fekete R, & Jankovic J (2014). The safety and efficacy of thalamic deep brain stimulation in essential tremor: 10 years and beyond. Journal of Neurology, Neurosurgery & Psychiatry, 85(5), 567–572. [PubMed: 24096713]

[3]. Krause P, Völzmann S, Ewert S, Kupsch A, Schneider GH, & Kühn AA (2020). Long-term effects of bilateral pallidal deep brain stimulation in dystonia: a follow-up between 8 and 16 years. Journal of Neurology, 267, 1622–1631. [PubMed: 32055996]

[4]. Salanova V, Witt T, Worth R, Henry TR, Gross RE, Nazzaro JM, … & SANTE Study Group. (2015). Long-term efficacy and safety of thalamic stimulation for drug-resistant partial epilepsy. Neurology, 84(10), 1017–1025. [PubMed: 25663221]

[5]. Cruz S, Gutiérrez-Rojas L, González-Domenech P, Díaz-Atienza F, Martínez-Ortega JM, & Jiménez-Fernández S (2022). Deep brain stimulation in obsessive-compulsive disorder: Results from meta-analysis. Psychiatry Research, 317, 114869. [PubMed: 36240634]

[6]. Martinez-Ramirez D, Jimenez-Shahed J, Leckman JF, Porta M, Servello D, Meng FG, … & Okun MS. (2018). Efficacy and safety of deep brain stimulation in Tourette syndrome: the international Tourette syndrome deep brain stimulation public database and registry. JAMA neurology, 75(3), 353–359. [PubMed: 29340590]

[7]. Gilbert F, Viaña JNM, & Ineichen C (2021). Deflating the “DBS causes personality changes” bubble. Neuroethics, 14(1), 1–17.

[8]. Hildt E (2006). Electrodes in the brain: Some anthropological and ethical aspects of deep brain stimulation. The International Review of Information Ethics, 5, 33–38.

[9]. Gisquet E (2008). Cerebral implants and Parkinson’s disease: a unique form of biographical disruption?. Social science & medicine, 67(11), 1847–1851. [PubMed: 18947914]

[10]. Schüpbach M, Gargiulo M, Welter M, Mallet L, Béhar C, Houeto JL, Maltete D, Mesnage V & Agid Y (2006). Neurosurgery in Parkinson disease: a distressed mind in a repaired body?. Neurology, 66(12), 1811–1816. [PubMed: 16801642]

[11]. Zuk P, Sanchez CE, Kostick-Quenet K, Muñoz KA, Kalwani L, Lavingia R, Torgerson L, Sierra-Mercado D, Robinson JO, Pereira S, Outram S, Koenig BA, McGuire AL, & Lázaro-Muñoz G (2022). Researcher Views on Changes in Personality, Mood, and Behavior in Next-Generation Deep Brain Stimulation. AJOB neuroscience, 1–13.

[12]. Lázaro-Muñoz G, McGuire AL, & Goodman WK (2017). Should we be concerned about preserving agency and personal identity in patients with Adaptive Deep Brain Stimulation systems?. AJOB neuroscience, 8(2), 73–75. [PubMed: 29238625]

[13]. Kubu CS, Ford PJ, Wilt JA, Merner AR, Montpetite M, Zeigler J, & Racine E (2021). Pragmatism and the importance of interdisciplinary teams in investigating personality changes following DBS. Neuroethics, 14(1), 95–105.

[14]. Houeto J-L, Mallet L, Mesnage V, Tezenas du Montcel S, Béhar C, Gargiulo M, et al. (2006). Subthalamic stimulation in Parkinson Disease: behavior and social adaptation. JAMA Neurol. 63, 1090–1095.

[15]. Temel Y, Kessels A, Tan S, Topdag A, Boon P, & Visser-Vandewalle V (2006). Behavioural changes after bilateral subthalamic stimulation in advanced Parkinson disease: a systematic review. Parkinsonism & related disorders, 12(5), 265–272. [PubMed: 16621661]

[16]. Appleby BS, Duggan PS, Regenberg A, & Rabins PV (2007). Psychiatric and neuropsychiatric adverse events associated with deep brain stimulation: a meta-analysis of ten years' experience. Movement disorders: official journal of the Movement Disorder Society, 22(12), 1722–1728. [PubMed: 17721929]

[17]. Castelli L, Perozzo P, Zibetti M, Crivelli B, Morabito U, Lanotte M, … & Lopiano L. (2006). Chronic deep brain stimulation of the subthalamic nucleus for Parkinson's disease: effects on cognition, mood, anxiety and personality traits. European neurology, 55(3), 136–144. [PubMed: 16682797]

[18]. Pham U, Solbakk AK, Skogseid IM, Toft M, Pripp AH, Konglund AE, … & Malt UF. (2015). Clinical Study Personality Changes after Deep Brain Stimulation in Parkinson's Disease.

[19]. Boel JA, Odekerken VJ, Geurtsen GJ, Schmand BA, Cath DC, Figee M, … & NSTAPS study group. (2016). Psychiatric and social outcome after deep brain stimulation for advanced Parkinson's disease. Movement Disorders, 31(3), 409–413. [PubMed: 26660279]

[20]. Kohl S, Schönherr DM, Luigjes J, Denys D, Mueller UJ, Lenartz D, … & Kuhn J. (2014). Deep brain stimulation for treatment-refractory obsessive compulsive disorder: a systematic review. BMC psychiatry, 14(1), 1–10.

[21]. Lhommée E, Klinger H, Thobois S, Schmitt E, Ardouin C, Bichon A, … & Krack P. (2012). Subthalamic stimulation in Parkinson's disease: restoring the balance of motivated behaviours. Brain, 135(5), 1463–1477. [PubMed: 22508959]

[22]. Merner AR, Frazier T, Ford PJ, Cooper SE, Machado A, Lapin B, … & Kubu CS. (2021). Changes in Patients' desired control of their deep brain stimulation and subjective global control over the course of deep brain stimulation. Frontiers in Human Neuroscience, 15, 642195. [PubMed: 33732125]

[23]. de Haan S, Rietveld E, Stokhof M, & Denys D (2015). Effects of deep brain stimulation on the lived experience of obsessive-compulsive disorder patients: in-depth interviews with 18 patients. PLoS One, 10(8), e0135524. [PubMed: 26312488]

[24]. de Haan S, Rietveld E, Stokhof M, & Denys D (2017). Becoming more oneself? Changes in personality following DBS treatment for psychiatric disorders: Experiences of OCD patients and general considerations. PloS one, 12(4), e0175748. [PubMed: 28426824]

[25]. de Haan S, Rietveld E, Stokhof M, & Denys D (2013). The phenomenology of deep brain stimulation-induced changes in OCD: an enactive affordance-based model. Frontiers in human neuroscience, 7, 653. [PubMed: 24133438]

[26]. Agid Y, Schüpbach M, Gargiulo M, Mallet L, Houeto JL, Behar C, Maltete D, Mesnage V, & Welter ML (2006). Neurosurgery in Parkinson's disease: the doctor is happy, the patient less so?. Parkinson's disease and related disorders, 409–414.

[27]. Funkiewiez A, Ardouin C, Caputo E, Krack P, Fraix V, Klinger H, … & Pollak P. (2004). Long term effects of bilateral subthalamic nucleus stimulation on cognitive function, mood, and behaviour in Parkinson’s disease. Journal of Neurology, Neurosurgery & Psychiatry, 75(6), 834–839. [PubMed: 15145995]

[28]. Thobois S, Ardouin C, Lhommée E, Klinger H, Lagrange C, Xie J, … & Krack P. (2010). Non-motor dopamine withdrawal syndrome after surgery for Parkinson’s disease: predictors and underlying mesolimbic denervation. Brain, 133(4), 1111–1127. [PubMed: 20237128]

[29]. Daniele A, Albanese A, Contarino MF, Zinzi P, Barbier A, Gasparini F, … & Scerrati M. (2003). Cognitive and behavioural effects of chronic stimulation of the subthalamic nucleus in patients with Parkinson’s disease. Journal of Neurology, Neurosurgery & Psychiatry, 74(2), 175–182. [PubMed: 12531943]

[30]. Mandat TS, Hurwitz T, & Honey CR (2006). Hypomania as an adverse effect of subthalamic nucleus stimulation: report of two cases. Acta neurochirurgica, 148, 895–898. [PubMed: 16763733]

[31]. Tsai HC, Chen SY, Tsai ST, Hung HY, & Chang CH (2010). Hypomania following bilateral ventral capsule stimulation in a patient with refractory obsessive-compulsive disorder. Biological psychiatry, 68(2), e7–e8. [PubMed: 20553748]

[32]. Muñoz KA, Blumenthal-Barby J, Storch EA, Torgerson L, & LÁzaro-MuÑoz G (2020). Pediatric deep brain stimulation for dystonia: Current state and ethical considerations. Cambridge Quarterly of Healthcare Ethics, 29(4), 557–573. [PubMed: 32892777]

[33]. Pugh J (2020). Clarifying the normative significance of ‘personality changes’ following deep brain stimulation. Science and Engineering Ethics, 26, 1655–1680. [PubMed: 32189235]

[34]. Kuckartz U (2014). Qualitative Text Analysis: A Guide to Methods, Practice & Using Software (1 Oliver’s Yard, 55 City Road, London EC1Y 1SP United Kingdom : SAGE Publications Ltd).

[35]. Braun V, & Clarke V (2006). Using thematic analysis in psychology. Qualitative research in psychology, 3(2), 77–101.

[36]. Boyatzis RE (1998). Transforming qualitative information: Thematic analysis and code development. sage.

[37]. Hennink M, & Kaiser BN (2022). Sample sizes for saturation in qualitative research: A systematic review of empirical tests. Social Science & Medicine, 292, 114523. [PubMed: 34785096]

[38]. Lázaro-Muñoz G, Pham MT, Muñoz KA, Kostick-Quenet K, Sanchez CE, Torgerson L, Robinson J, Pereira S, Outram S, Koenig BA, Starr PA, Gunduz A, Foote KD, Okun MS, Goodman W, McGuire AL, & Zuk P (2022). Post-trial access in implanted neural device research: Device maintenance, abandonment, and cost. Brain Stimulation, 15(5), 1029–1036. [PubMed: 35926784]

[39]. Merner AR, Fins JJ, & Lázaro-Muñoz G (2022). Brain Device Research and the Underappreciated Role of Care Partners before, during, and Post-Trial. AJOB neuroscience, 13(4), 236–239. [PubMed: 36272159]

[40]. Lewis CJ, Maier F, Horstkötter N, Zywczok A, Witt K, Eggers C, … & Timmermann L (2015). Subjectively perceived personality and mood changes associated with subthalamic stimulation in patients with Parkinson’s disease. Psychological medicine, 45(1), 73–85. [PubMed: 25066623]

[41]. Mosley PE, Robinson K, Coyne T, Silburn P, Breakspear M, & Carter A (2021). ‘Woe betides anybody who tries to turn me down.’A qualitative analysis of neuropsychiatric symptoms following subthalamic deep brain stimulation for Parkinson’s disease. Neuroethics, 14, 47–63.

Table 1.

Personality-Related Benefits Reported by Participants

Emotional State
"I used to just enjoy life or enjoy everyday things or just enjoy life a little bit more. And I definitely feel that's back." (OCD1) "It's just made me a lot more outgoing, back to where I was before OCD. It's just made me a lot more happy-go-lucky." (OCD2) "I'd say it definitely improved a lot of my anger. It took a lot of my anger away. And it's not the anger that it took away, it took some of the tics and it took a lot of pain that was caused by the tics that I was doing. A lot of anger can from that. So it definitely helps with that." (TS1)
Meaningfulness
"As far as my personality or anything, just more positive, more upbeat, uplifting, and hopeful, and a greater desire to live life and to do all of these things I've been dreaming of doing. I'm not talking about life goals or life dreams, but just all the small things that we take for granted until we lose them. Just getting out of the house and being outside, especially now that the weather is beautiful, and everything's green and blooming and colorful." (OCD3) "A big surgery, to have brain surgery is huge. And then going through the recovery and everything, it just makes you be more humble, just being more … I don't know what the word is, but just understanding yourself." (DYS1) "I have more confidence and a brighter outlook for the future than before. I was really worried about how I was going to be in 10 years." (PD1)
Feelings of Focus or Presence
"Before my implantation and the turning on two weeks later of the device, of the DBS, I wasn't able to be there as much, for one thing I was sleeping so much, for them, and missing out on a lot. Now, I don't want to be asleep." (OCD3) "I'm so, so happy that I got it done. I'm just a better person. I'm a better mother. I'm there. I'm present now and I don't worry about unnecessary things." (OCD4)
Openness
"Yeah, it's opened me up more to the world. That's what I'm trying to say. Where before I was closed off and metaphorically in the corner in a ball not wanting anybody near me, not wanting to be out in the world and living life and things, and now I'm out of that corner, on my feet joyfully, and rejoicing in God's blessing and the blessing of the DBS, and Dr. [CLINICIAN]" (OCD3)
Interpersonal Relationships
"I think it's helped me to be a little more outgoing. It helped me to be more engaged in conversation and relationships with people." (PD2) "A lot of people see it around, people around me sees it. I think I'm more calmer. I'm easier to communicate with. I'm a lot easier to talk to right now than before." (TS1) "When I'm with my mom, which is usually most of the time, usually on weekends, I guess I find myself kind of… Maybe more kind of being a little more silly with her… Maybe opening up a little bit more to her." (OCD5)
Confidence and Agency
"I guess I'm a little more confident now. I certainly appreciate the fact that I can go out on a golf course and I haven't been able to do that for six years. So I'm not worried if I hit a bad shot because I'm just enjoying being out there and I'm happier." (ET1) "Also the ability to voice things I want or don't want. That had all kind of shut down due to OCD. I couldn't talk about food or talk about what I wanted out of anything or food or if we wanted dinner, I couldn't have a part of that because of OCD and being able to just do the everyday things, things that are normal for most people, being able to have those things back the way that I felt before the OCD was super crazy strong." (OCD1) "I think it's coming on slow, but yes. Just being more confident and more assertive. More not afraid to do different things, ask questions and so on." (DYS1)

Table 2.

Participants Reports of Negative Personality-Related Changes

Unwanted emotionality
“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.” (ET2) “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 because nowadays, oh my God, if I go to a support group it’s like I feel like issuing a warning. Warning, I could get extremely emotional over nothing.” (PD6)
Temporary post-surgery cognitive/affective issues
“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.” (ET2) “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.” (ET1)
Talkativeness following stimulation adjustments
“[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.” (OCD5)
Increased anxiety
“I preface this because I don’t know if it’s the DBS or if it’s progression of the disease. I think it’s more progression of the disease. I do have a little more anxiety than I traditionally have had. And so that’s something that I have to get used to.” (PD3)

Table 3.

Participants Reporting Return to a Pre-Disorder Sense of Identity

Identity
"It's made me more me. It's made me who I'm supposed to be, more outgoing and more this thirst for life and living it to its maximum." (OCD3) "I'm more me than I ever was before." (PD5) "If anything, it makes me feel more like I am the real me. I have the chance to once again be more like the real me, because the real me is very movement oriented." (PD6) "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." (PD1)

Table 4.

Participant Descriptions of Autonomy-Related Improvements

Self-Confidence
“I’m not as timid getting out in public anymore. I feel pretty good. I just feel better. I think it’s confidence that I’ve been feeling.” (PD1) “I think it makes me feel more confident that I can do some things because I’m just not shaky. I wouldn’t try some things because I knew they were going to get me in trouble, but now I can do them.” (ET1) “I seem more confident in myself, more motivated, go out and do things with people, whether it was working or going out to a bar with friends or just hanging out. I wasn’t as self-conscious as I was” (TS2) “I’m not self-conscious anymore. And I was starting to get over my self-consciousness before I had the DBS done, but now I have no self-consciousness anymore at all, about anything, like I used to… I’m a lot more confident” (PD5)
Activities of Daily Living
“I can get dressed easier. I don’t need as much help doing things like that. Personal hygiene and stuff like that. There were times where I’d have steak or something and I couldn’t really cut it. I just didn’t have the coordination. That’s not problem anymore.” (PD1) “I’m able to do a lot more things than I was. So before, for example, I could do things like cook and wash dishes, but it could be fairly challenging at times, you know? …Now it’s really way more routine so I can help with a lot of stuff… I help a lot more than I did. I’m able to go out, do laundry, and go out in the garden, which is really nice.” (PD6)
Greater Freedom
“I have more freedom. That’s basically the way I see it… just being able to do things and not have Parkinson’s interfere with life as much.” (PD7) “I do feel like I’m living a lot more the way that I want to live or choose to live. I feel I have much more of a choice over that or an influence over that. With the OCD as bad as it was before the DBS, I felt like I didn’t have a choice at all. I was so rigid. So since the DBS, I definitely feel like I have a lot more, I don’t know, opportunities for quality of life and enjoyment of things.” (OCD1) “[W]ith this newfound freedom, like I said, I’ve opened up to the world. I’m more open to doing things I was afraid to do, I was terrified to do, before… like going to the grocery store and things like that, and getting out” (OCD3).* *This same participant, who before DBS felt “trapped inside,” now felt “free and released from the shackles of obsessive-compulsive disorder.” The participant described DBS as facilitating a “breakthrough” that was to occur later in the day: “I’m about to make a huge breakthrough; it’s the moment I step outside in the backyard. The first time in two decades.”
Greater Independence
“I always had to rely on my husband or other people to do things for me… Now I don’t have to wait for him to come home… I can just go out and do things by myself, and be more independent” (OCD4). “I’m starting to be a little more independent with some things… I can make my own bed. I’ve gotten to do a few more things on my own lately, rather than relying on other people to help me with it” (TS3).
General Improvements
“[B]efore, I felt especially different from other people, like I was on a different life course and everything…Now, I think I’m just like other people. I feel like other people and can make the same kind of plans and stuff. I just have a bit of a balance issue, very occasional tremor and some medicines to take.” (PD4) “Oh, they [motor tics] were bad. They were constantly, nonstop. But now, I do it four times, maybe every 20 minutes, but it’s not constant like before. It used to be torturing, like I can’t sit down without me sweating nonstop because I’m moving constantly nonstop. So it definitely is a good sign it helped a lot.” (TS1) “Prior to having the DBS surgery, I would have severe anxiety to the point where I’d be sweating. I could not focus on my job. I couldn’t focus on anything I wanted to get done. My social relationships, they strained. It just made life 10 times harder for me. So I had to call out of work a lot. I couldn’t focus on what I needed to get done, so it was just pointless for me to be there. But since then, I haven’t called out of work at all.” (OCD2) “Whenever my family would come and visit, I wouldn’t really want to go out to certain places. Or if I was in a really bad mood, I just wanted to stay in indoors. Or I just wanted to be in bed all day, and just not live life. That’s why when you said that, it’s changed my life drastically. That’s what I mean, I’m actually living my life now. I have my life back.” (OCD4)

Table 5.

Participant Descriptions of Autonomy-Related Concerns

Autonomy Concerns
“There is a restriction now that I have to be careful with hitting my head and crushing these implants. I lean against something or just playing around with my grandkids or something.” (PD1) “[A]fter having that stimulation for months, and then having it turned off even for a minute, for 30 seconds, or when it shut off, when the battery went to zero, it was way worse. I was way worse than I was before. My anxiety went through the roof… I absolutely need it now. My body, my brain, whatever, is I guess, used to it or is dependent on it now.” (OCD3) “[I]t seems like I’m more run down after the deep brain stimulation. That is I feel a little bit more tired, and I have to drink some energy drinks, some coffee, to help kind of wake me up in the morning. It’s usually when I wake up. It takes longer than normal to get going.” (TS2) “I have slurred speech I never had before. I can be speaking, I get stuck on words and stutter because I’m trying to think of what I want to say and I can’t get it out. And my balance right after surgery was kind of… It was real bad after surgery…Most of that has went away. I would say I have a slight balance problem. I drag my right foot a little bit. I notice that I lift my foot up more. So, there’s a few after effects I have, but it’s not that big of a deal because I’m happy that my right hand doesn’t shake anymore.” (ET2)

Table 6.

Participant Descriptions of Improved Physical Status and Functional Ability

Physical status and functional abilities
"…one of the most scary things would be waking up in the middle of the night and having to go to the bathroom because my balance might be in question. Seriously. I mean, in the worst cases. And now it's not an issue at all." (PD6) "I was functioning, but before it was just that my Tourette's was getting in my way. And now, just tic less and improving. I feel like life is getting better for me." (TS1) "And I think the biggest thing was I had rigidity in my muscles, […], and sometimes they would be so rigid it would be really painful. And in the worst case, all I could do was get into bed and just deep breathe, you know? So my back, I just don't have much of any rigidity now." (PD6) "Even using a computer used to be difficult, trying to use a mouse and things like that, and that's not a problem anymore." (ET3)
Medication reduction
"I think medication was a big deal, being on and off, and I was taking probably, I think every two hours I was taking medicines so I could keep myself, at least somewhat functional. Right away, right after the DBS surgery, I was taking two thirds less Sinemet. So I take it two pills, three times a day, before I was taking three pills, five times a day, quite a bit. So I have less brain fog. I'm able to be more mobile, active. I have more on time instead of off." (PD2).

Table 7.

Participant Descriptions of Improved Psychological Status and Well-being

Mood/emotionality
"My thoughts are better, my body is getting better, stronger, and so I'm just… It's kind of a big question. How am I living? It's just a better kind of life with my mindset and my body and my overall being is more positive." (DYS1) "I love life and I want to live it to its fullest. Before I couldn't, and then I grew apathetic, I didn't care over the years, and I was hopeless and severely depressed. Now, all that is gone and there's basically a new me and it's wonderful, truly wonderful, amazing, beyond what I could put into words for you. I'm doing the best I can, but it's just a blessing from God that is beyond measure, beyond what I can really and fully comprehend." (OCD3) "It gives me the mindset to think positive and keep going with life." (TS1)
Existential
"There's actually a hope to live. There's a hope for the future and there's enjoyment back into regular life things." (OCD1) "I feel absolutely wonderful, and amazing, and hopeful, and forward-looking to my future with great hope and anticipation, and now I'm thinking again about living life." (OCD3) "It gave me a second chance at life." (TS1)
Clearer or less rigid thinking
"…able to be more active, I have more on time and I have more, my cognitive thinking seems to be a little more clear" (PD2). "It was a constant battle every waking moment with stuff like that, with the contamination fears, with being trapped inside and not going outside for weeks or months at a time. The DBS has changed all that" (OCD3). "Just being a little more open about things. Trying to remember to be open-minded and not so closed off. That's really hard for me because the open-minded, sometimes, because the OCD, the rigidity of thinking, when you're in it, is just insane." (OCD5)
Improved interpersonal relationships
"I can run errands with my husband, I can hang out with friends, hang out with family. I can regularly attend my boxing classes." (PD7) "I spend time with my little brother. We'll play video games sometimes. Once in a while, I do some stuff for my mom, to help her in the house." (TS3) "And now just regular day-to-day basic every day, I'm trying to go out with my friends, go out to do stuff, go skating, play soccer with them. I couldn't do that. And now I'm thinking about redoing that all over again, which is that's the DBS giving me a second chance in life, to be honest." (TS1) "Relationships would be a huge one and really just every day, things. Being able to function, being able to sit in the same bed as my husband, being able to share food with my mom or just really the everyday things is what has made that quality of life so much better." (OCD1)

Table 8.

Participant Descriptions of Remaining Challenges or Lack of Change to Quality of Life

Remaining challenges to quality of life
“But I’m not going to lie, it’s not all, what is the phrase? Roses and butterflies or, you know? It’s still a struggle. But not like before.” (OCD5)
“I could see it was on a downward trend, as far as mobility and ability to keyboard and work. And since the deep brain stimulation, there’s been some recovery. I can also tell that it’s long-term, there’s going to be a decline, but it appears to be much slower now.” (PD3).
“I think I had a very good quality of life. I don’t or never have had severe tics. So it never really affected anything that I did unless, I guess, it was socially or going certain places where you needed to be quiet. So I don’t think it really had much effect on my quality of life.” (TS4).