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RESEARCH ARTICLE

Adolescent OCD Patient and Caregiver Perspectives on Identity, Authenticity, and Normalcy in Potential Deep Brain Stimulation Treatment

Jared N. Smith[1], Natalie Dorfman[2], Meghan Hurley[1], Ilona Cenolli[3], Kristin Kostick-Quenet[1], Eric A. Storch[4], Gabriel Lázaro-Muñoz[3] and Jennifer Blumenthal-Barby[1]

[1]Center for Medical Ethics and Health Policy, Baylor College of Medicine, Houston, TX, USA; [2]Department of Philosophy, University of Washington, Seattle, WA, USA; [3]Center for Bioethics, Harvard Medical School, Boston, MA, USA and [4]Psychiatry & Behavioral Sciences, Baylor College of Medicine, Houston, TX, USA
Corresponding author: Jared N. Smith; Email: smith.jaredn@gmail.com

Abstract
The ongoing debate within neuroethics concerning the degree to which neuromodulation such as deep brain stimulation (DBS) changes the personality, identity, and agency (PIA) of patients has paid relatively little attention to the perspectives of prospective patients. Even less attention has been given to pediatric populations. To understand patients' views about identity changes due to DBS in obsessive-compulsive disorder (OCD), the authors conducted and analyzed semistructured interviews with adolescent patients with OCD and their parents/caregivers. Patients were asked about projected impacts to PIA generally due to DBS. All patient respondents and half of caregivers reported that DBS would impact patient self-identity in significant ways. For example, many patients expressed how DBS could positively impact identity by allowing them to explore their identities free from OCD. Others voiced concerns that DBS-related resolution of OCD might negatively impact patient agency and authenticity. Half of patients expressed that DBS may positively facilitate social access through relieving symptoms, while half indicated that DBS could increase social stigma. These views give insights into how to approach decision-making and informed consent if DBS for OCD becomes available for adolescents. They also offer insights into adolescent experiences of disability identity and "normalcy" in the context of OCD.

Keywords: agency; authenticity; children; deep brain stimulation; identity; normalcy; obsessive-compulsive disorder

Introduction and background

Deep brain stimulation (DBS) is a form of neuromodulation being actively researched and used in treating several different treatment-refractory movement and psychiatric disorders.[1,2,3,4,5,6] DBS involves surgically inserting leads into the brain which deliver controlled electric stimulation to areas targeted for symptom relief, much like the effects of ablation but without the need for permanent lesions.[7,8,9] Initially indicated for essential tremor and Parkinson's disease, the efficacy of DBS for these applications has led to a surge in research on its viability for treating a variety of other conditions, including: major depression,[10,11,12,13,14,15,16] dystonia,[17,18,19,20,21,22,23,24] Tourette's syndrome,[25,26,27,28,29,30,31,32] Alzheimer's/dementia,[33,34] epilepsy,[35,36,37,38] and obsessive-compulsive disorder.[39,40,41,42,43] In the United States, DBS is FDA-approved to treat essential tremor, Parkinson's disease, and epilepsy and is approved under Humanitarian Device Exemption (HDE) for adult obsessive-compulsive disorder (OCD) and for pediatric dystonia.[44,45] DBS has typically been viewed as an invasive "treatment of last resort," although the ethics surrounding this conceptualization (as well as the definition of "refractory") are debatable.[46,47,48,49,50] While DBS for OCD in the United States is currently restricted to adults, given positive findings of efficacy in treating adult OCD, the HDE for pediatric dystonia, and the potential clinical utility of DBS for severe and treatment refractory OCD in adolescents, it is likely DBS may be used in the future for this purpose. As such, our study investigated prospective attitudes toward DBS among adolescent OCD patients and their caregivers.[51] Previous studies on DBS for OCD have typically solicited and analyzed perceptions of DBS treatment for OCD among clinicians, adults with OCD, and parents of children with OCD.[52,53] Ours is the first study we are aware of to present youth patient perspectives on the impact of both OCD *and* DBS on personal identity, authenticity, and the social sphere.

There is robust and ongoing discussion in the neuroethics literature surrounding whether (and to what degree) DBS and other forms of neuromodulation influence an individual's identity.[54,55,56] Several interrelated and overlapping concepts have found purchase in this debate: personality, identity, autonomy, authenticity, agency, and self (collectively referred to as PIAAAS). While philosophers and bioethicists have developed technical definitions of these terms, there is no single agreed upon conceptual framework in neuroethics, and so these terms are often used in different and sometimes conflicting ways.[57,58,59,60,61,62] For example, Peter Zuk and Gabriel Lázaro-Muñoz point out that there are (at least) three substantive (and non-coextensive) conceptions of "autonomy" theorists may appeal to.[63] Furthering the complexity of this debate, the interplay and connections between these related identity concepts are not standardized, either—although there have been efforts to systematically connect some of them.[64,65,66,67,68] For example, we might think that one's personality is part of, but not reducible to, her identity—or that the only sense of agency worth wanting is authentic agency, and so on.

While there is a significant literature debating the potential for DBS to cause changes to PIAAAS, there has been considerably less investigation into pediatric patient views on their first-hand perceptions of their identity. We are unaware of any previous study that presents patient perspectives on identity and authenticity in potential DBS for youth with severe OCD. These perspectives are important for neuroethics researchers to get a better sense of how would-be adolescent DBS patients construe the possible impacts to PIA. Integrating first-person perspectives and concerns with the existing normative frameworks for understanding changes to PIA is integral to properly conceptualizing changes to the self for pediatric and adolescent DBS patients.

In what follows, we present our main findings on adolescent and caregiver perspectives on identity and DBS in relation to severe OCD and situate our analysis of these findings within the larger neuroethics literature. We begin with stakeholder perspectives on the salient theme of "*normalcy*" and its relationship to the way DBS may impact the adolescent's social sphere. From there, we review respondent perspectives on the possibility of changes to self-identity and *identity formation* more generally from both potential DBS treatment and OCD itself. Finally, we present stakeholder perceptions of the potential impact to *authenticity* from DBS and OCD. In our discussion, we suggest that the connection stakeholders make between the social sphere and identity may mean patients and caregivers are conceiving of identity in a relational sense (as has been proposed before by some authors).[69,70,71] We conclude by suggesting that future studies engaging stakeholders on these topics include explicit investigation and analysis of the concept of "disorder" or "disability" identity for potential DBS patients, given our preliminary findings on this topic.

Methods

Participants & procedures

Table 1 includes demographic information for caregiver respondents and Table 2 includes demographics for patient respondents. Note, one caregiver and one patient were excluded from analysis, but their demographic information is included in the tables below.

We conducted semistructured interviews with U.S.-based adolescent patients with severe OCD ($n = 21$) and their caregivers (e.g., parents) ($n = 19$) regarding their perspectives about potential future DBS treatment. Our team developed an interview guide, drawing from salient issues in the neuroethics and neurostimulation literature as well as discussions with experts in both DBS and movement disorders

Table 1. Caregiver demographic information

Caregivers	*n* = 22	%
Gender		
Male	3	13.6
Female	16	72.3
No response	3	13.6
Race/ethnicity		
Hispanic/Latinx	1	4.5
White or European American	18	82
Asian	1	4.5
No response	2	9.1
Age		
41–45	4	18.2
46–50	7	32
51–55	5	23
56–60	3	13.6
No response	3	13.6

(e.g. pediatric dystonia). An advisory team reviewed drafts of this guide, which was also piloted by a psychiatrist working on refractory OCD in both adults and adolescents, and adjusted accordingly. Our study was approved by the Institutional Review Board at Baylor College of Medicine.

Patient and caregiver respondents were asked about projected impacts to identity, including authenticity of emotions and behaviors. Interviewers asked respondents the following questions:

1. *Adolescence is considered a key period for identity formation. Do you think pediatric* ***DBS*** *will have an effect on your identity?*
2. *Do you think pediatric DBS could affect the extent to which you perceive your* ***emotions*** *as your own as opposed to coming from the device?*
3. *Do you think pediatric DBS could affect the extent to which you perceive your* ***behaviors*** *as your own as opposed to coming from the device?*
4. *Can you tell me a little bit about the history of your OCD symptoms and just when you first started noticing them? How has* ***OCD*** *impacted your identity?*

The concepts of "authenticity" and "identity" were left open to stakeholder interpretation and were not defined by interviewers beyond what is outlined above (e.g., authenticity = your own versus the device's thoughts, feelings, behaviors; identity = self/perception of self). We return to this point about respondent operationalization of authenticity in our discussion.

Data analysis

Interviews were transcribed and coded in MAXQDA 2018 and 2020 software and processed for thematic content analysis to isolate and compare specific themes across cohorts. More detailed methods for this study may be found here.[72]

Table 2. Patient demographic information

Patients	*n* = 20	%
Gender		
Male	3	15
Female	12	60
Trans male	1	5
Nonbinary	1	5
Prefer not to answer	0	0
No response	3	15
Race/ethnicity		
Hispanic/Latinx	5	25
White or European American	12	60
Prefer not to answer	0	0
No response	3	15
Age		
14	4	20
15	0	0
16	3	15
17	2	10
18	0	0
Prefer not to answer	8	40
No response	3	15

Results

Social impact, stigma, and potential for "return to normalcy"

Half of patients with OCD (52.6%, 10/19) expressed the belief that DBS could have a positive impact on social identity, particularly allowing them to return to "normal." Specifically, patients indicated that DBS would allow them to engage more fully in society by decreasing OCD symptoms. As one patient expressed, "…you're not doing the compulsions and stuff all day, kind of, you can go back, you can get a job, you can make, get summer jobs or something. You can do stuff that normally you wouldn't have time for," (PT_006).

Despite half of patients believing DBS could positively impact their social identity, half (52.6%, 10/19) also voiced a concern that social isolation and stigmatization could arise due to DBS treatment. Furthermore, nearly one-third (31.5%, 6/19) expressed concerns that because so few of their peers or individuals in the world have a DBS device, DBS could make them look different from others and increase existing stigma. As one patient discussed stigma within the general community:

> "Just having like a medical device implanted is something that not many people have to deal with… [Even] medication is still pretty stigmatized. And at least in my high school, not among my group of friends, but just the wider community. Like when you take medications it's like, 'Oh, you really can't

> deal with it on your own?' So, I feel like having some device implanted would kind of extrapolate that and on a teenager that could be very hurtful" (Pt_03).

Notably, fewer than one-third of OCD caregivers (28.57%, 6/21) stated that DBS would have a positive impact on the social identity of the patient, and a minority (14.3%, 3/21) stated that DBS would likely cause social isolation and stigma.

Impacts of OCD and DBS on identity formation

We asked respondents about the impact of both OCD (actual) as well as DBS (prospective) on identity formation. A small portion of caregivers (5/21 or 23.8%) and patients (7/19 or 36.8%) voiced that OCD impacts identity formation, with 2 (9.5%) caregivers and 6 (31.6%) patients expressing that OCD is "world-closing" in that it prevents them from fully accessing society. A minority of respondents (3/21 Cg and 1/19 Pt) indicated that the symptoms of OCD are not constitutive of the patient's true or authentic personality.

Half of all OCD caregivers (52.3%, 11/21) and *all OCD patients* (100%, 19/19) projected that DBS would likely impact identity formation. Of patients who expressed that DBS would alter their self-identity over half (58%, 11/19) believed that DBS could have a positive impact on identity by allowing them to explore their identities more and free them from significant OCD symptoms. These caregivers were more mixed about the potential identity impacts of DBS, with 54.4% (6/11) of this subgroup responding that they believed DBS could have positive identity impacts and 45.45% (5/11) responding they were unsure about the identity impacts.

The views that patients and caregivers voiced about impacts to identity were vastly different. For example, nearly half of patients (47.4%, 9/19) expressed that needing a significant intervention like DBS could disrupt patient identity, as DBS would be an instant cure instead of allowing patients to engage in the critical work of therapy to control OCD. As one patient said, "I would see my former person as weak and that I was only good enough when I was being helped by someone else" (Pt_16). Another stated, "A person who had DBS could maybe wonder what their character would be like if they had worked through all that therapy and all that struggle" (Pt_13). Patients expressed questions about the implications of receiving DBS on their character and self-perception, specifically whether the intervention would decrease their self-esteem and make them feel as though they are "cheating" in terms of a recovery process. Interestingly, no caregivers voiced such a concern.

Over half of caregivers (6/11, 54.5%) and patients (11/19, 58%) who indicated DBS may impact identity expressed that DBS could have a *positive* impact on identity formation. Patients expressed that freedom from debilitating symptoms would better allow for self-discovery. As one patient responded, "I would just be able to experience more and find out who I am without the OCD, because it's pretty big part of me and it takes up a lot of time" (Pt_07). Caregivers echoed the sentiment that DBS would allow patients to explore their self-identity and highlighted the potential improvements in quality of life that come from a more gradual treatment process or intervention. One caregiver stated, "[…] obviously [treatment] makes them feel better if they're not dealing with whatever depressions or OCDs that may have made their lives nonfunctioning" (Cg_15). This potential freedom of self-discovery that DBS may allow is important for stakeholders in carving out an identity distinct from their OCD. As one adolescent remarked:

> "I think by getting rid of the distraction of OCD would help a lot. I struggled a lot with identity and trying to find out who I was and what I liked and what I didn't. I think OCD played a huge part of it because it just [destroyed] me and gave me this negative and unreal view of life and how life should be. I think that if DBS were to take that away it would make that process so much easier of finding yourself and what you like and don't." (PT_15).

However, nearly half of these caregivers (5/11, 45.5%) had conflicting views on the nature of impacts of DBS on identity. Some caregivers expressed having a hard time balancing the benefits of DBS (e.g., decreased symptoms) with the potential downfalls (e.g., stigmatization due to intervention). As one caregiver explained "It would maybe help their self-esteem and their confidence if their symptoms are lessened, but kids are… you don't want other kids to know that your kid has an implantable device in their head for psychological problems" (Cg_14).

One incidental, minor finding was that a few patients (2/19, 10.5%) expressed perspectives on changes to disorder or disability identity from DBS, unprompted. Since respondents were not explicitly asked about these concepts, this view may have been shared by others but not voiced. One such patient expressed strongly identifying as disabled, and being concerned that DBS would minimize their disabled identity. The patient likened the relation of OCD and identity with that of autism, stating,

> "I feel that OCD is a part of my identity, and I wouldn't be who I would…I just, I wouldn't be myself without OCD. And I have friends, I've a friend who is autistic and she wouldn't be herself without autism. I can't imagine her without it, just like I can't imagine myself without OCD." (PT_08).

This patient also wondered about the impact of treatments like DBS on disability broadly: "Do you go in and take away all their disabilities or problems and leave them perfect? […] you're eliminating something that makes someone who they are". This sentiment shows the importance that some OCD patients place on preserving their disability (or disorder) identity. The other patient expressed that others who strongly identify with having OCD as a disability would likely struggle with the transition from having debilitating symptoms to functioning normally. The patient explained that "I think that could really help, but at the same time, if that's all you were, which hopefully no person is, then how do you feel if you don't feel that way anymore? … It's a huge transition" (Pt_18).

Impacts of DBS on authenticity

Most adolescent respondents (73.7%, 14/19) and nearly half of caregivers (43%, 9/21) believed that DBS would impact patient authenticity in some way. Of those respondents, nearly all patients (85.7%, 12/14) and most caregivers (66.7%, 6/9) expressed concerns about the potential for DBS to create *negative* impacts on self-perceived authenticity. Patients and caregivers were largely concerned that DBS would alter the patient perception of emotions being "theirs" and create feelings of being controlled, which might in turn lead to a feeling of inauthenticity and lack of self-trust. As one patient expressed, "Yeah, I think there will definitely be some concerns about whether or not their emotions were coming from [the patient] or the device," (Pt_16). Caregivers who had concerns expressed similar sentiments, with one explaining that, for the patient, "the whole surgery piece, and… putting something in [his brain], might make him think he's changed … It could definitely have some negative consequences of him not identifying with him being himself," (Cg_15).

A small minority of both patients (2/19, 10.5%) and caregivers (9.5%, 2/21) reported that DBS would not have *any* impact on self-perceived authenticity of personality and emotions. One such patient explained that "any type of device, medication, therapy is going to have an effect on you. At the end of the day, this device is not actually going to change your personality and your emotions directly. It's going to trigger you to think differently and have a different outlook," (Pt_15).

Discussion

"Return to normalcy" and the social sphere

As Christian Saleh and Gregor Hasler point out, despite social functioning being one of the key outcomes for young patients with psychiatric conditions, there is relatively little focus on this in the neuromodulation literature. They provide evidence suggesting that DBS can improve social functioning in those with psychiatric conditions, which is supported by other recent DBS research.[73,74,75] Adolescent respondents in our study spoke about hope for increased social functioning in terms of a kind of "normalcy" and did not ascribe negative features to the concept or experience (as is the case in the conceptual history of "normalcy" in disability theory, for example).[76] As patient respondents discussed it, a return to normalcy had a positive social dimension of allowing greater access to social activities and friend groups. In this way, adolescent respondents predicted that DBS would accommodate the patient's navigation of both the physical and social world. In this sense, DBS was viewed as potentially "world opening" for adolescents whose social opportunities and experiences have thus far been restricted by their symptoms.

Despite predicting DBS facilitating increased social access, a meaningful portion of patients worried that having DBS surgery and an implanted device may stigmatize them among their peers. Caregivers were comparatively less concerned about the potential for stigmatization. This difference may relate to the elevated concern adolescents (generally) have about social acceptance and social groups, and participation in social contexts like school classes, sports, and friendship outside of school (as compared to adults). Robyn Bluhm et al. point out that the emphasis from neuroethicists on potential changes-to-self following DBS may have a stigmatizing or chilling effect on those considering DBS, making them less likely to consider it.[77] This would add to whatever stigma exists about neurosurgery more generally, although until quite recently little was known about public perceptions of DBS or stigmatized attitudes towards it. There may be some recent empirical support for this impact—Laura Y. Cabrera et al. report that members of the public without a psychiatric diagnosis had concerns about neurosurgery (for psychiatric conditions) specifically surrounding the authenticity of the agent's thoughts and actions, worrying that changes in symptom experiences and expressions may not reflect the person's true self.[78] Similarly, Bluhm et al compare the perspectives of psychiatrists, patients, and members of the public on "electroceutical interventions" (including DBS) for depression, finding that respondents from the public believed DBS could have myriad (positive and negative, direct and indirect) impacts on personality and sense of self.[79]

Some theorists have suggested that the disruptions some DBS patients experience (which are often cast as changes to PIA) are best understood in terms of psychosocial adjustment, with these difficulties representing a syndrome termed the *burden of normality* (BoN).[80,81] The BoN was initially theorized based on postoperative psychosocial adjustments observed in epilepsy patients receiving neurosurgery and has since been documented following neurosurgical interventions for various conditions including Parkinson's disease and OCD. As Frederic Gilbert describes it, "The BoN syndrome describes the adjustment response process following efficacious psychosurgery, when patients suddenly change from 'chronically ill' to 'well' or 'seizure free'."[82] More generally, the BoN can be understood as the dissonance a person experiences which results from their difficulty adjusting to their newfound ability and self-conception in comparison with their previous impairment.[83]

In one striking and germane case study, "Mr. A" had OCD which was so severe and treatment resistant into early adulthood that he was unable to live alone or care for himself and was limited in his ability to leave the house. Following DBS surgery and calibration, he experienced a staggering reduction in his symptom severity (YBOC score reduction from 30 to 6 eight months after surgery meaning subclinical symptoms). With this result, he had so outstripped the goals of therapy he set for himself when ill (e.g., attend college, begin dating) that he struggled to determine who he was and adjust every aspect of life without OCD. As he remarked to researchers, "I was confronted with all these new feelings and not knowing how to react to things, being well, like there was a set way that I'd react to situations when I had OCD. I knew what I would do. But now that I'm well, when a situation comes up, I don't know how to react." This was incredibly distressing and something for which he felt ill-prepared. This leads him to suggest pre- and postoperative support for the burden of normality for future OCD patients receiving DBS.[84]

Identity changes in deep brain stimulation and OCD

While the fact that some DBS patients experience what we might broadly call changes to the self after DBS treatment is empirically supported,[85,86,87,88,89,90] how best to *characterize* these changes (and how worried we should be about their looming specter) is widely debated.[91,92,93,94,95,96,97] Recent empirical work reveals that some researchers view positive changes to identity as in some sense the *intended* effect of DBS for certain conditions; we might think there is something deficient in DBS for psychiatric conditions like OCD if there are *no* such changes. Peter Zuk et al. 2023 point out a slight tension between the primarily negative way some of the neuroethics literature depicts such changes versus evidence that patients receiving DBS experience it positively.[98,99] Our findings reinforce Zuk et al.'s suggestion that such a tension exists. Remarkably, all adolescent respondents in our study stated that DBS would impact identity in some way, with half suggesting such changes would be positive. That some adolescents expressed that DBS could offer an opportunity to find out "who I am without OCD" indicates the structuring role the disorder plays in their experience of experiences of self and aligns with previous findings from adults with OCD who describe the barrier OCD has presented to their self-conception and identity.

An unanticipated and novel theme emerged among some adolescents who voiced some variation of the idea that DBS for OCD might represent a kind of "cheating"—taking the easy route to overcoming OCD. Regarding adolescent identity formation, this represents a concern that DBS may rob patients of the opportunity for growth that comes from developing other strategies for managing OCD (e.g., ERP). On the one hand, this concern speaks to Mr. A's suggestion of the prudence of pre- and post-DBS support to prepare patients for changes they may experience relating to their ability to achieve goals, engage in self-care, and so on. On the other hand, considering that DBS for OCD is currently only used as a last resort for treatment refractory cases, there is an expectation that candidates for DBS have already attempted ERP and other interventions without relief and so less of a concern of missed opportunities for personal development.

A nascent (but promising) thread emerged in a minority of patient and caregiver responses concerning identity that may be of interest for future researchers: the role of what we have called a "disorder" or "disability" identity. Recall that several respondents in our study expressed a concern about the role that *OCD as a disorder* has had on developing their personal identity, echoing similar thoughts on the part of post-DBS adult OCD patients about who they would be as a person if not for their OCD.[100,101] This is striking given Sanneke de Haan et al.'s point that lacking a robust pre-OCD identity (as might be the case in adolescent patients) complicates the question of whether DBS helps a person become "more oneself." While this idea of "becoming more oneself" is a theme in some recent DBS research, we are unaware of any work explicitly engaging with the way DBS impacts self-conception of disability or disorder/disability related to one's personal identity specifically. This could be a fruitful avenue of future research in understanding the transition from pre-DBS to post-DBS life and better preparing patients for the possibility of such changes or difficulties. In their recent adaptive DBS study, Amanda Merner et al. do not find significant impacts on identity, although a fuller exploration of this requires further research with a larger and more diverse sample set.[102] While there has been some work on brain computer interface (BCI) devices and embodiment re: physical disability and embodiment, there is little of this exploration in BCIs for primarily psychiatric conditions.[103]

Me or OCD? Authenticity and DBS

Directly related to personal identity and self-conception is the concept of *authenticity*. Some symptom experiences of OCD can concern authenticity, as in moral thought-act fusion where thinking about some event is seen as equivalent to the event actually occurring or makes it more likely to occur, as well as the search for meaning or importance in intrusive thoughts.[104,105] In thought-act fusion, a person with OCD can fear that an intrusive thought with repugnant content is reflective of who they are. For example, in postpartum OCD, obsessions about harming one's child (which are contrary to the parent's character) may make a parent fear they will severely harm their child, as Windsor Flynn recounts.[106] Another example can be found in "feared-self" obsessions (e.g., relationship OCD or sexual orientation OCD) where obsessions are interpreted as having significance for who a person is.[107]

A significant literature addresses authenticity in the context of identity changes due to DBS; however, one important and under-evaluated factor relates to the idea of ego-dystonic symptoms. Much of the psychological literature characterizes many of the intrusive thoughts (i.e., intrusive thoughts of a sexual nature or violent images) that are symptoms of OCD to be *ego-dystonic*.[108,109,110] Ego-dystonic symptoms are ones that are dissonant from the perception that one has of oneself, which makes the individual view these symptoms as inauthentic to themselves. The ego-dystonic nature of most OCD symptoms is particularly relevant in light of our finding that most patients with OCD were concerned that DBS would have negative impacts on self-perceived authenticity. While patients believed that DBS could decrease symptoms and allow greater access to society, of the adolescent patients who expressed a concern about DBS leading to inauthenticity, most (85.7%, 12/14) expressed concerns that DBS would create feelings of being controlled and a perception that emotions were not "theirs", which would significantly impact feelings of authenticity and self-trust.

While many patients expressed wanting to decrease the experience of ego-dystonic thoughts and emotions, some were also wary of the potential for DBS to create new, different kinds of ego-dystonic emotions. Some caregivers also expressed a concern that DBS could lead to a feeling of being controlled, which related to the ego-dystonic symptoms constitutive of most experiences of OCD. This concern that DBS could "contribute" its own set of ego-dystonic symptoms or exacerbate existing symptoms is important to address with patients if DBS or other neuromodulation device were medically indicated for this population.

Conclusion

First-person perspectives on concerns and prospective changes following DBS are crucial for understanding and addressing questions and concerns patients may have when considering neuromodulation. Our study has highlighted both hopes as well as concerns from adolescent patients with OCD and their caregivers on changes to PIA from deep brain stimulation. The potential for approval of DBS as an intervention for adolescents with treatment-resistant OCD adds urgency to these critical questions about personality, identity, and authenticity in the context of both ordinary development and neurostimulation interventions. Our findings highlight the need to understand first-person patient and caregiver perspectives, considering the perceived potential impacts to self. One interesting, minor finding that we noted was that some patients with OCD had expressed a strongly held "disability identity" that they were worried would change due to DBS. Future studies may benefit from asking respondents explicitly about identification with being disabled and potential impacts to identification with disorder or disability due to DBS as well as a more thorough investigation of patient views on how OCD has shaped their development as a person.

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