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The lived experiences of individuals with Tourette syndrome following anterior-medial globus pallidus internus deep brain stimulation: an interpretive phenomenological analysis

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ABSTRACT

Purpose: Tourette syndrome is a debilitating neurodevelopmental disorder. Despite the recent increase in the use of deep brain stimulation for the treatment of refractory Tourette syndrome, few qualitative studies have explored the post-surgical experiences of individuals. This research aimed to explore the lived experience of individuals who underwent deep brain stimulation for Tourette syndrome.

Method: This qualitative study was informed by the phenomenological design. Semi-structured interviews were conducted with the first cohort of five individuals to have undergone anterior-medial globus pallidus internus deep brain stimulation in South Africa. Interpretative phenomenological analysis was utilised to analyse the data.

Results: Four key themes were identified: (1) Battle with Tourette syndrome; (2) Temporal journey with deep brain stimulation; (3) Transformation: (Re)constructing the self in context after deep brain stimulation; and (4) Fusion: brain, technology and me.

Conclusion: Living with Tourette syndrome was described by the participants as a fight for control, with symptoms having profound effects on family and social relationships. Identity reconstruction following surgery was complex, but treatment led to a change in social interactions and personal growth. Improvement was not immediate but rather a gradual process to find optimal settings. Most participants managed to integrate the device successfully into their identity.

IMPLICATIONS FOR REHABILITATION

- Tourette syndrome is a complex disorder impacting physical, psychological and social functioning.
- Deep brain stimulation is a neurotherapeutic treatment option for refractory Tourette syndrome, yet limited research is available on the lived experiences of individuals following deep brain stimulation.
- Clinicians should provide comprehensive pre-operative counselling and neuropsychoeducation to patients and their families regarding the expectations, risks and psychosocial implications of deep brain stimulation.
- They should provide continuous multidisciplinary patient management and psychological support to address adjustment challenges, optimise outcomes and monitor psychosocial well-being after surgery.
- In addition, they need to adopt an integrated and individualised rehabilitation approach informed by multidisciplinary perspectives.

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Introduction

Tourette syndrome (TS) is a childhood neurodevelopmental disorder that typically presents with vocal and motor tics, increasing in severity until early adolescence [1,2]. Among some patients, remittance of symptoms occurs in adolescence and early adulthood (Ghosh and Ghosh [3]) [4]. Despite pharmacological and behavioural therapies, some individuals have persistent and severe symptoms, complicated by

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the presence of psychiatric comorbidities [5]. Alternative treatments through other modalities beyond medication management and psychological therapies are often considered in these cases [6].

Advancements in neural interface technology has allowed for the development of new neurotherapeutic methods to treat movement and neuropsychiatric disorders [7–10]. One such method is deep brain stimulation (DBS), a neuromodulatory procedure targeting various brain structures. Deep brain stimulation is a neurosurgical intervention in which electrodes, delivering controlled electrical stimulation, are implanted into specific brain regions to help modulate abnormal brain activity and relieve symptoms. The procedures generally take between 4 and 8 h and include surgical preparation, lead and neurostimulator implantation, followed by post-surgical modulation. In recent years there has been an incremental increase in the use of DBS for the treatment of refractory TS. Brain regions such as the centromedian-parafascicular complex of the thalamus, anterior limb of the internal capsule and globus pallidus interna are targets typically considered for DBS [5,11,12]. Although research supports DBS efficacy for tic reduction [13], this surgical procedure is complex and invasive and its use for TS is still considered experimental [14].

Known adverse outcomes of DBS include complications with hardware malfunction, post-surgical infection and physiological and psychological consequences of stimulation such as dizziness and anxiety [6]. Researchers have therefore highlighted the importance of further studies into the ethics of DBS for both adults and children, as what it means to live with DBS post-operatively is poorly understood [1,6,15]. Shahmoon et al. [16] highlighted that while there may be benefits associated with surgery, it also comes at a personal cost. Quantitative results from TS studies demonstrate post-DBS clinical efficacy pertaining to symptom reduction and improved quality of life [9,17,18]. However, studies on movement disorders such as Parkinson's Disease and TS showed that patients may experience self-estrangement in part due to the technological nature of DBS [19–21] and changes in personality, behaviour, mood and cognition [1,22,23] (Mosley et al. 2019). While the clinical-motor benefits of neuromodulation in TS are well known, its integration into the social model of disability and the neurodiversity paradigm is significantly more complicated, raising questions about identity, agency and the neuroethics of technologically-assisted interventions [24–26]. This complexity derives from the individualised-deficit based perspectives on neurological differences that often overlook the exclusionary contexts that make living with neurodivergence more difficult [27]. Understanding the neuroethics of DBS and TS patient perceptions before surgical consideration may promote clinical practices that incorporate neuroinclusivity and neuroaccessibility. Deep brain stimulation may further require social adjustments as it impacts relationships with family and friends [16,22]. The reduction of pre-existing symptoms, the addition of new symptoms, and the affective experiences after surgery may change how patients interact with others and how they are viewed and supported in return.

There is a paucity of qualitative studies exploring post-surgical experiences associated with DBS. As current literature focuses on objective outcomes measured with standardised clinical questionnaires, improvements in quality of life and symptom reduction are quantified, yet they lack the sensitivity to capture the overall experiences of change from the perspective of individuals with TS [16]. Although these objective outcome measures offer clinically useful information, a positive change in symptoms on a questionnaire may not necessarily translate into a positive experience in the patient's life. The complexity of living with a chronic neurodevelopmental disorder is often experienced as a disruption in one's sense of self and a process of reconstruction of identity in a way that accommodates the condition [11,12,28,29]. A systematic review on evolving illness perceptions by Petter et al. [30], offers insights into how individuals with TS may experience sudden symptom alleviation following DBS differently because of their experiences of living with TS and the myriad of meanings they attach to experiences. These unique perspectives support further research and may provide valuable knowledge that informs multidisciplinary post-surgical interventions for optimal DBS outcomes. Additionally, it will allow for a more informed decision-making process, management of post-surgical expectations, better preparation for patients and caregivers on potential psychological outcomes and a person-centred assessment of treatment efficacy [15,31].

Given potential risks, neuroethics, adverse effects, unexpected outcomes of treatment and that TS is a childhood disorder where surgery may be performed many years post-diagnosis, understanding post-surgical experiences is integral to long term treatment goals and interventions. However, quantitative measures cannot adequately capture TS patient experiences of living with DBS [16] and researchers recommend further qualitative enquiry on the lived experiences of DBS [1,15,32]. This study aimed to explore the lived experiences of anterior-medial globus pallidus internus (amGPi) DBS in the first South African TS cohort to undergo surgery.

Method

Design

The research design followed a phenomenological approach, grounded in phenomenological and hermeneutic philosophy. Phenomenology is a qualitative method that aims to understand and describe the common meaning individuals attribute to their lived experiences and perspectives of a central phenomenon [33]. In line with hermeneutic principles, the researchers are actively involved and engage in double hermeneutics by interpreting the participants' interpretations of their lived experiences [34]. The goal is to provide a deeper understanding of how individuals understand and make sense of their experiences.

Participants

In South Africa, following extensive multidisciplinary workup that included neurological, neuropsychiatric, surgical and neuropsychological screening procedures for DBS suitability, the first TS cohort was selected for amGPi-DBS. Patients were evaluated and treated at three specialised movement disorder centres. The five patients were contacted in 2023 by the neurologist who was involved in the initial DBS screening process. An information letter detailing the purpose, objectives and methods of the study was provided to the participants. Following this recruitment process, the researchers contacted the patients as all five consented and provided them with further information and obtained written consent prior to participation. Given the small sample size and that all patients were presently in adulthood no further limitations to inclusion were applied.

Data collection

In-depth semi-structured interviews were conducted with the participants in 2023–2024 to discover how they experience living with DBS. The interview guide was self-developed with reference to existing DBS literature and informed by the principles of Interpretive phenomenological analysis (IPA). Questions were open ended and referred to participants daily life before DBS surgery and what living with DBS meant to them now. They were asked to reflect freely and in detail on their experiences and provide in-depth accounts of their thoughts, emotions and behaviours. Questions related to positive and negative experiences within their daily lives and further probed successes and difficulties relating to life with DBS. Finally, participants were asked to reflect on personal as well as social experiences. The interview guide provided a consistent framework for all interviews while additional probes were used to explore specific details or narratives as emphasised by the participants.

Interviews were conducted virtually and audio recorded after oral participant consent. The interviews took place at a time convenient to the participants. Virtual interviews were conducted as most participants lived in other provinces and cities a distance away from the specialised movement disorder centres. Interviews ranged from 45 to 60 min. A member of the research team (JM), who was not involved in the DBS workup or had previous contact with patients, conducted the interviews.

Data analysis

IPA is a qualitative research technique that is used to explore the subjective experiences of individuals. IPA is particularly useful for studying human experiences and perceptions in small samples, as it aims to understand how people make sense of their experiences and the world around them [33,35]. The analysis seeks to uncover the participants perspectives, meanings and interpretations of their experiences, and as such is suitable for analysing how the participants experience living with DBS.

To enhance the quality of the study as the sample size was small, interviews were detailed and open-ended to allow participants to freely and in detail express their experiences and perspectives. The interviews were transcribed verbatim to ensure that the meaning of the participants was not lost or distorted. Two research team members (NC & JM) analysed transcripts line by line, and wrote exploratory notes to capture initial observations. Using these notes, experiential statements were then formulated, after which statements were clustered around central connections or contradictions [35]. From these

clusters, personal experiential themes were derived for each transcript. Once each transcript was analysed, cross case analyses was conducted to determine group experiential themes across transcripts [35]. All personal identifiers were removed from the data to ensure confidentiality. Digital recordings were password protected and only accessible to the research team.

Ethical considerations

Participants who have received amGPi-DBS and currently living in their communities were recruited to participate. They were fully informed of the nature of the research and informed consent, together with permission to be part of the study was requested from the participants. Confidentiality was maintained by using codes and pseudonyms on transcripts, and following the university regulations data was stored electronically (password protected), accessible only to the researchers. The researchers are cognisant of the fact that DBS surgery is an invasive procedure. While questions related to living with DBS, as opposed to surgery itself, participants who felt distress as a result of participating in the study, had the option of contacting the research team member (NC), a board-certified neuropsychologist working in the field of DBS surgery. The details of this referral process were outlined in the information letter provided to prospective participants. The present study was reviewed and approved by the authors' university ethics committees (Humanities and Health Sciences).

Positionality statement

NC is a self-identified Indian female academic-researcher-clinician with experience in the field of movement disorders and DBS. I acknowledge that my interpretations are shaped by my professional background, values and assumptions about neurodiversity, disability and medical interventions, and I aimed to maintain reflexivity throughout the study to ensure participants' experiences were represented authentically.

JM is a self-identified White female academic with limited exposure to or experience with movement disorders. Being a researcher external to the clinical DBS team potentially reduced any perceived power imbalances and allowed for a curious stance during interviews. This encouraged participants to share their lived reality as experienced by them by prioritising the participants' accounts as the sole source of knowledge construction. However, it may have limited probing into clinical or technical aspects of their experience.

RvC is a self-identified White male clinician–researcher. I recognise that my professional background and experiences with Tourette syndrome and DBS shape my interpretations and remained reflexive throughout the study to recognise and manage potential biases, ensuring that participants' lived experiences were represented with authenticity and respect.

The process of engaging with the data during collection, analyses and write-up was reflexive and supported by frequent discussions between NC and JM, and RvC was debriefed throughout the process.

Results

Table 1 outlines the characteristics of the TS cohort.

The data analysis identified four principal themes. These themes, together with associated subthemes, elucidate the profound implications of living with TS and the transformative trajectory associated with DBS.

Table 1. Sample characteristics ($n = 5$).*

Pseudonym	Gender	Family History	Age at surgery
James (P1)	Male	√	25
Olivia (P2)	Female	√	17
Daniel (P3)	Male	√	26
Michael (P4)	Male	X	34
Luke (P5)	Male	√	16

*Refer to Kisten et al. (24), for detailed DBS surgical procedure, patient information and clinical characteristics.

Theme 1: battle with Tourette syndrome

This theme encapsulates participants persistent struggles with TS as a pervasive force disrupting their existence. They consistently characterised their pre-DBS experience as a protracted battle, delineated by three subthemes.

Sub-theme 1.1: fighting for control

Participants experienced TS as an external, controlling force that severely impacted their basic functioning, often leading to a struggle for control over their bodies and actions. The externalisation of TS was evident in participants' descriptions: James consistently referred to his motor tics as "The twitch," Olivia felt "possessed," and Luke recalled: "I can't even know where it comes from. I hit people next to me, I just can't control myself." The constant management of extreme symptoms, including coprolalia and self-injurious behaviour, disrupted daily functioning. For instance, Luke shared, "My mom used to feed me because I used to eat and like I would just stab myself with a fork." Daniel similarly illustrated the challenges of routine tasks, noting, "Getting dressed at times was taking me half an hour," demonstrating how motor tics impeded basic activities. In addition, vocal tics rendered some participants unable to "even say like one sentence" (Olivia). In extreme instances, the severity of symptoms necessitated extraordinary measures, such as physical restraint for Luke's self-injurious behaviour, leaving him "tied up on the bed" (Luke).

Pharmacological therapies were utilised in an attempt to manage symptoms of TS. However, participants portrayed medication management as a balancing act between symptom relief and the treatment side effects. For some, pharmaceutical interventions were as debilitating as TS, as was the case with Olivia noting her medication was "actually like killing my organs." Most participants described how medication induced a form of personal and cognitive detachment. Daniel shared, "I was like a walking zombie," while Olivia reflected, "I wasn't living life. I was just like, in a body," and James similarly stated that he felt merely "on autopilot." Notably, three of the five participants used the term *zombie* when describing their experiences with TS or its pharmacological treatment, suggesting a pervasive sense of being disconnected from life.

Confronted with these challenges, participants described their persistent struggle against TS, striving to maintain a semblance of control and a desire for normalcy: "I just want to be like a normal person" (Michael). However, despite the adversity, not every participant felt they lost the battle. For Daniel, even though "it was the worst time of my life," he attempted to maintain perspective and felt that he "learn[t] how to manage it in a certain way. I saw myself as a young man that needs to live his life and it's holding me back, but I did the best I could, in every situation."

Sub-theme 1.2: impact on family and social relationships

TS resulted in profound social consequences, including strained familial and interpersonal dynamics. Participants reported feeling different from others, expressing a desire for normalcy, while simultaneously confronted by negative reactions from others, including bullying and name calling. This lack of understanding from others often precipitated feelings of shame, embarrassment, humiliation and perceived judgement. Michael illustrated this experience: "people used to mock me about it. If they see me, then they'll do a twitch or something." The nature of their symptoms frequently necessitated family and friends having to serve as intermediaries in social situations, as exemplified by Olivia's experience: "I'd run away and cry and then my sister or my mom or my dad would have to talk to the person, the friend, or the teacher at school or the kids at school and the teacher would have to explain afterwards to all the students." Consequently, several participants expressed feelings of being a burden to their family, with all participants experiencing social isolation. For Olivia, the sole female participant, this impact was potentially exacerbated by her unique circumstance of having a twin sister without TS, creating a point of comparison that may have emphasised her perceived difference.

Luke's experience was particularly severe, as the need for physical restraint led to extreme social isolation: "I used to be tied up, my hands used to be tied up behind my back. I used to lay on the bed for the whole day." This physical confinement, combined with negative responses from others – "…they call me names and say ugly things about me," – had extreme psychological consequences: "I didn't

want to live anymore. I just hated myself. I blamed myself for it because big people blamed me for it" (Luke).

Some participants recognised the impact TS had on their family members, particularly in witnessing their suffering. Daniel expressed empathy for his father who had to witness his self-injurious behaviours: "I just kept on hitting and hitting [his own head] and he couldn't do anything, he was in tears… It took a big toll." Similarly, Olivia noted her twin sister "went through a lot to try to protect me," adding that she (Olivia) "hated it how much I put them through."

Sub-theme 1.3: desperation and hope

This sub-theme captured participants journeys towards choosing DBS. Participants had exhausted all other alternatives, including attempting extreme treatment options. All participants viewed DBS as a last resort, with varying levels of expectation regarding outcomes. For instance, Olivia "didn't have any expectations. All I had was hope," while others had specific expectations for improvement: "I thought it would really help me" (Luke), or even a cure: "I wanted to be healed" (Michael). As the first TS-DBS patient in the country, Daniel was "very scared" but was desperate enough that he "was a guinea pig, but I was ok with that." It is interesting to note that many participants accepted the risks of surgery, underscoring their experiences in sub-theme 1.1 of disconnection from life as a result of TS. For instance, Olivia expressed that she "was so far gone with my Tourette's syndrome that if I'd died [as a result of surgery] I would have also been ok with that."

Theme 2: temporal journey with DBS

This theme captured the progressive experience of DBS treatment, from preparation for surgery to ongoing adjustments of device settings for symptom control during regular follow-up appointments with the medical team. While all but one participant described the treatment in some way as "life-changing" (James), it was not without its challenges. The preparation process was particularly difficult for some participants. For Daniel, the resurgence of TS symptoms caused by stopping all medication in preparation for surgery proved to be difficult: "I was just trying to get through day by day." Many participants also found the initial post-surgical period challenging, particularly Olivia:

> I thought I was unlovable, I thought that, oh my gosh, I have no hair and I am chubby, no one's ever going to love me, my friends are going to leave me. And… I just thought that I was hideous. I thought that I'm going to be lonely forever

Expectations prior to surgery appeared to influence participants' experiences immediately after the procedure. For Michael, there was "disappointment" when his hopes for a cure were not met. However, all other participants reported at least some immediate improvement post-surgery. Importantly, the journey to symptom improvement took time for these participants. Quantifiable improvement occurred over several months or even years as device settings were adjusted and optimised. Finding optimal settings was not immediate but rather a process of "trial-and-error" (James), and James acknowledged that "it's hard to find optimal settings," while Daniel similarly revealed, "It takes months to set it right and I didn't know that." Some participants also reported short-term discomfort when their settings were adjusted. Daniel described feeling "anxious" and experiencing "pins and needles in my whole body for like thirty, forty seconds," while James noted an impact on his sleep: "When the voltage was too high then I wasn't sleeping nicely."

For some participants improvement took time. For instance, for Olivia "The surgery only started helping properly, I would say probably drastically about two, three years after my surgery." This experience led participants to reframe their view of DBS to a tool for assistance instead of a cure. As Daniel explained, "I don't think there's any more improvements you can do with this operation. It's never one hundred percent but the rest I take medication for and that balanced it out." For Luke, who had previously been restrained and isolated, the improvement was particularly noticeable: "Everything has changed. Everything. I'm like a normal person now."

While every other participant reported substantial improvements in TS symptoms over time, Michael's experience diverged notably. Following adjustments in his settings, he reported experiencing adverse

psychological effects described as "going into a depression" (Michael). Furthermore, Michael's decision to discontinue follow-up appointments (ascribed to distance; "we can't really leave here" and time; "we've also been busy") coincided with different outcomes. Without proper device adjustments, he experienced worsening symptoms over time and attributed the negative changes to the device itself: "I don't know if there's maybe a wire loose or I don't know because it's just getting worse and worse." However, while admitting to altering the device settings himself: "We've been going down with it, we want to try and put it off completely and to see," throughout the transcript it was clear that he did not associate the self-administered decrease in stimulation to his continued (and worsening) symptoms. In contrast, James, for whom DBS was "life-changing," stated: "The settings and functions are controlled by (the doctor), so I don't play around with that" suggesting an understanding of and respect for the need for device management by professional medical personnel.

In addition to the above, the psychological impact of surgery and treatment is particularly important. Despite substantial improvement in the physical symptoms of TS ("My Tourette's was like ninety-nine percent better"), Olivia developed both a substance and an eating disorder after surgery, which she partially attributed to feeling "unlovable" as a result of physical changes post-DBS. However, the influence of DBS treatment on identity also emerged as a critical factor, explored further in Theme 3.

Theme 3: transformation: (re)constructing the self in context after DBS

This theme encompassed three distinct subthemes related to post-DBS identity, social interaction, and personal development.

Subtheme 3.1: change in self and identity

This subtheme revealed the complex processes of identity reconstruction following surgery. Since participants had incorporated TS into their identity, the loss of TS (for all but Michael) required a shift in self-perception and identity:

> I was always Olivia with Tourette's and then I was just Olivia after my DBS after my Tourette's was gone. So, I always had to find something or something to do or someone to cling on to, to give me my thoughts of identity

For three participants, the change was immediate and positive, leading to an enhanced sense of self. While Daniel stated that "it didn't change who I am, but it changed how I could handle life," James felt his personality changed "for the better," and Luke shared that "now I'm just happy and nice." In contrast, Olivia's experience was more complex, initially finding the change difficult: "I had no self-worth, no identity, I didn't know who I was… I felt like I lost who I was, which was Tourette's." Reflecting on the loss of her TS-based identity, she said: "It's something that I guess, I had to grieve and say goodbye to." After over two years of counselling, she ultimately reached a more positive redefinition of her identity and self-concept: "I feel good about myself. I feel like I have a good personality, I'm funny, I'm lovable" (Olivia).

Even though Michael did not experience a reduction in TS symptoms, he reflected on an altered sense of self, though he struggled to articulate the specifics of the change: "I think since I got it, it has changed me as what I was before this. I can't explain, I just feel different," likening it to "almost a split personality." When probed, he revealed that his assessment referred to mood swings that "just comes and goes." It remains unclear whether these mood swings are related to DBS device stimulation, psychological factors stemming from his continued TS symptoms, or perhaps a combination of the two.

Subtheme 3.2: change in social interaction

This subtheme highlighted the improved social functioning and family relationships of participants who maintained regular follow-up care. The reduction in symptoms allowed all four of these participants to feel "normal" (James, Olivia, Daniel, Luke), underscoring their previous perception of themselves as different to others before DBS. This led to decreased social isolation, with improved social functioning and directly attributed to the reduction in symptoms. Daniel described this transformation: "I can talk to people without having tics, outbursts." This improvement was particularly important for participants with

vocal tics, who referenced being able to hold "proper" and "normal conversations" after DBS (James, Olivia, Daniel), highlighting the importance of typical communication in maintaining social interactions and perceptions of belonging.

The reduction in symptoms also led to positive changes in family relationships. Participants described how they felt more integrated within their families, no longer perceived themselves as burdens and experienced closer relationships with family members. Their family members, in turn, were "happy" (Luke) about the participants improvements. Olivia exemplified this sentiment:

> We can talk, we can do family gatherings together, we can laugh together, we don't have to hide from each other, we don't have to walk on eggshells around each other, or them around me. We're like a normal family now.

In contrast, Michael's discontinuation of follow-up care and subsequent suboptimal device settings resulted in ongoing social difficulties and isolation. He described feeling "embarrassed and uncomfortable, like I can't be around people" and expressed a longing for the normality that the other participants had achieved: "I just want to be like a normal person where I can go and sit in a building in front of people and knowing not to worry are those people behind me watching me now." Michael also relied heavily on his partner for support in social contexts because of his continued TS symptoms: "That's why I always want him with me, so he can help me talk."

Subtheme 3.3: personal growth

Personal growth was evident among participants who maintained regular follow-up care, describing increased empathy for others, the development of new interests and hobbies, and participation in advocacy roles. There appeared to be a shift from an inward, "selfish" (Olivia), focus on their "unbearable" (James) battle with TS to an outward focus on helping others. For Daniel, this desire to help specifically related to educating others living with TS in order to "change [their] lives" (Daniel). For Olivia, this desire was more general, expressed through her aspiration to help others by becoming a teacher: "I feel like this is my calling, to help children and to get them the right education that they need." Similarly, James reflected on how his experiences with TS and DBS had made him "more empathetic and understanding," and shared he had: "become a lot more helpful and I definitely give more charity. I just feel like I'm a kinder person after this whole thing." In comparison, Michael did not demonstrate similar personal growth. Instead, he described feeling as though he had "completely gone dead," and stated that "Sometimes, I wish I can cry, just to feel like I'm a human." These quotes reflect the disconnection from life as experienced by the other participants prior to DBS, and is thus potentially linked to his limited engagement with the treatment process and therefore continued battle with TS.

Theme 4: fusion: brain, technology & me

This theme explored participants acceptance of the DBS device as part of their sense of self and lifestyle. All participants who maintained regular follow-up care described successful integration of the device into their identity. While all participants remain aware of charging the device, some participants initially needed time to adjust to the device within their body, but eventually became unaware of it on a daily basis. For example, Luke noted: "it doesn't hurt at all, I don't feel it in my body at all." However, for Daniel, this period of adjustment was lengthy: "with the wires in my head and stuff it took me about two or three years to get used to them." Participants developed routines for charging the device, which did not appear to be problematic. As Olivia explained: "I have to charge the pacemaker once a week, but I always remember to do that because… it's part of my life" (Olivia). Although some were cautious of potential injuries, such as Daniel avoiding rugby ("I can't play rugby") and James being wary of head injuries ("maybe just not get hit in the head"), they largely viewed the device as a medical tool that enabled them to be the "best version of you" (Daniel).

In contrast, Michael struggled to integrate the device into his sense of self and viewed it as an additional restriction, stating that "it just won't allow me to go do the stuff that I want to do." He described avoiding certain objects, such as generators, fans, hairdryers, or "anything with a motor coil," as well as pylons: "I can't go near that." He also reported feeling constrained while travelling, as airport security

procedures required adjustments for him to pass through: "at the airports they need to turn those machines off for me to go through." Michael's difficulty integrating the device was further reflected in his statement: "there's not supposed to be currents or electrical things going through your brain. I mean it doesn't sound normal."

Discussion

This study highlights the intrapersonal and social challenges of living with TS and the potential transformative role of DBS treatment.

Participants experienced TS symptoms as an uncontrollable and overwhelming force. They perceived their lives with TS as an extreme battle between physical and psychological duality that impacted their sense of agency and ownership and self-determination; aspects that Rae et al. [36] and Curtis-Wendlandt [37] described as the conflict between premonitory sensations and tic action. This duality may be characterised as a tension between a self that wants to project a socially acceptable image and sensory 'neurological' reprieve (tics) [38], which essentially further reflected participants' fragile self-world boundaries and the different processes of merging with a TS self. The diminished interactive agency and lack of self-coherence with the world in terms of meaningful interaction accentuated the social isolation felt by participants, who longed for a normality disrupted by TS. Previous research on the experiences of living with TS highlighted this conflict between concordance and estrangement incorporating TS into self-identity (Malli and Forester-Jones [39]). The ambivalent feelings of desperation and hope informed participants journey towards DBS treatment. For many, DBS was seen as a last recourse, an option they were willing to embrace despite its risks, with some individuals expressing an almost fatalistic acceptance of the risks.

Baylis [40] proposed a relational perspective on personal identity, which frames the current study participants accounts of the social impact of TS described through the personal identity lens of relationships with family, friends and society. In keeping with previous research findings [41,42] regarding stigmatisation and stereotypes, this study found that the stigma of TS led to bullying, misunderstandings, and, in some cases, self-blame, shame and social isolation. As Merner et al. [21] found, TS not only disrupts the individual but also alters family dynamics, sometimes resulting in a deep sense of guilt and burden for both the individual and their caregivers

The importance of continuous setting optimisation, treatment adherence and multidisciplinary professional oversight following surgery is illustrated by the trial-and-error journey to symptom improvement and the complex post-surgical challenges of a disorder that transcends mere symptom alleviation [10]. The emotional cost of waiting for improvements was characterised by difficult post-surgery periods where some participants struggled with feelings of low self-worth, exacerbated by the physical changes they underwent. This aligns with existing literature, which has found that adjusting to a new normality and the changes to illness representations brought about by DBS can be difficult, particularly for individuals who have lived with chronic conditions for an extended period of time [1,20,43].

Despite some initial setbacks, for most participants, the long-term benefits of DBS became evident over time and supported the findings from several studies reporting positive changes in general quality of life [11,12,21]. The reduction in symptoms allowed many participants to reclaim a sense of normality and agency in their daily lives. The findings of Moore et al. [44] and the typologies of normality proposed by Sanderson et al. [29] offer insights into the present study results. TS distorted patients sense of normality, transforming their lives into a struggle for normality characterised by unpredictable medication effects that caused a mutable sense of normality. Following DBS there was a retuning or return to normality and a continued reconstituted normality for most participants. This is illustrated in their newfound ability to communicate more easily, to interact without the fear of uncontrolled tics disrupting conversations, or to engage in activities they once avoided. There was an awareness of a transformative and meaningful shift internally and in relationships with others, post-DBS. Michael's decision to stop attending follow-up appointments led to worsening symptoms, setbacks and a deeper sense of self-estrangement.

Adjusting to life after DBS was a complex journey. For many, TS had been so deeply ingrained in their self-identity that symptom alleviation through DBS required a psychological process of evolution and redefinition. Olivia, for example, experienced a symbiotic relationship with TS, and post-surgery alienation

reflected a sense of loss and grieving for this relationship, followed by a process of reconstitution of her symbiotic agency with neurotechnology. According to several studies, the challenges of living with pervasive symptoms of TS and the challenges of living without TS symptoms mediated by neuromodulated brain is a complex process [21,37,45]. Young women have to further navigate the merging of gender identity and a TS identity and the complications that this imposes [46].

According to Gaille [32], a complex and important aspect of DBS patient's lived experiences is the relationship with an implanted technological device. Integrating the DBS device into their daily lives touched on participants sense of authenticity, questioning who or what is controlling their mood and behaviour. Moreover, the findings of this study aligned with researchers views that perceptions of integration and shared control between the person and the implanted neuromodulator can re-establish some level of agency [45]. For many, the device reflected a synergetic part of their reconstituted self, aligning with the notion of an implanted prosthetic that allowed them to lead more fulfilling lives (Gilbert et al. [47]). However, Michael's story provides a stark contrast. He was reluctant to fully embrace the device, rejected shared autonomy and perceived it as restrictive, both physically and psychologically, which appeared to have a considerable impact on his outcomes. For those who embraced the device, it became less of an obstacle and more of a facilitator, allowing them to explore different versions of themselves. It should, however, be noted that Michael was the oldest patient to undergo DBS surgery and had lived with TS for the longest duration among the study cohort. This may conceivably have influenced his expectations, outcomes and decision to discontinue follow-up care. His experiences underscore the importance of considering individual patient histories and circumstances when recommending DBS, preparing individuals for treatment, and planning post-surgical follow-up care. Attending to these factors can help mitigate risks, manage expectations and improve long-term outcomes.

Advances in neuromodulation raise questions about neuroethics and the intersectionality of invasive interventions and neurodiversity, emphasising the importance of self-determination in treatment choices [21,25]. Participants' narratives illustrate that their experiences of symptoms are not only socially stigmatised but also self-injurious and disruptive to daily functioning. They describe both relief and ambivalence relating to the alleviation of tics, alongside concerns about identity changes and the sense of being "different" after surgery. In such circumstances, DBS may be perceived not as a means to conform, but to potentially reclaim a sense of agency. When framed as a means to improve physical and psychological quality of life; DBS, neurodiversity and social disability model principles may intersect, provided that the intervention is voluntary, identity-affirming, and situated within a larger framework of acceptance and inclusion [11,12]. Situating DBS within the social model and neurodiversity movement may be determined less by the neurotechnology itself, but rather by the context. and consideration of whether DBS is imposed as a cure, or chosen as one of many options that value and accommodate neurodivergence. Being mindful of the neuroethics allows for better DBS patient preparation protocols and cognisance of how this translates to clinical practice.

An important pre-operative step involves the careful management of patient expectations and agency in decision-making. Participants in the present study were uncertain about what to expect regarding outcomes, and unrealistic expectations left some disappointed. Preparation for DBS surgery should therefore ensure that patients understand DBS is a tool for symptom management rather than a cure for TS. Additionally, the participants highlighted the lengthy time to find optimal device settings. Pre-operative consultations should therefore also address this potential period of adjustment to ensure post-operative compliance.

Psychological preparation before surgery is also important, given the identity reconstruction experienced by the participants. Providing patients with psychological support prior to and after surgery, particularly regarding the loss of TS as a defining aspect of their identity and the shift in identity following DBS, may reduce the emotional and psychological challenges faced by some participants. Moreover, as noted by many participants, family support was an important factor before and after surgery. Neuropsychoeducation for family members prior to surgery, and family therapy after surgery, may enhance their understanding of both TS and DBS and prepare families for potential psychological and practical adjustments. The differences in experiences reported by the only female participant in the present study further suggest that pre-operative preparation may need to account for individual differences. These include factors such as gender, age and developmental needs, as this may influence patient experiences.

Post-operatively, the findings suggest that discontinuing follow-up appointments for device adjustment, and independently adjusting the device settings, may lead to lack of device integration and worsening of TS symptoms. Patients should therefore be prepared for and strongly encouraged to comply with, long term follow up treatment. Given that some participants described short term discomfort immediately after settings were adjusted, informing patients of this potentiality may alleviate anxiety around the experience. Additionally, as highlighted by the experiences of one participant, concerns around electromagnetic interference should be addressed to reduce anticipatory anxiety and feelings of lifestyle restriction. Where device management was accepted, participants described increased social interaction. Social engagement programmes such as peer support groups, digital communities and arts (e.g. music, drama) therapy may support social skill development and quality of life where patients have experienced severe isolation, as described by some participants in this study.

According to Alare et al. [41], encouraging access to neurotherapeutic interventions in Africa begins with the understanding of socio-cultural beliefs and stigmas associated with neurological disorders. Experiences of discrimination and social stigma highlight limited public awareness at both schools and the community at large. Educational campaigns incorporating the socio-cultural heterogeneity of this sub-Saharan African country and addressing various cultural perceptions of TS are a key driver to addressing stigma and discrimination. Given the desire for advocacy roles expressed by most participants, perhaps they are well suited to contribute to the development and dissemination of awareness campaigns, especially in a country with a heterogenous socio-cultural context.

Strengths and limitations

A limitation of the study was the small sample size due to the lack of DBS surgical procedures carried out on individuals with TS. The latter characterises the challenges encountered in the African context [48] such as funding model disparities for public and private healthcare and availability of specialised centres and professionals involved with DBS and movement disorders. As a result of the small sample size detailed demographic information for the participants could not be provided without risking their anonymity. Furthermore, the sample differed in terms of age, onset of TS and comorbidities and the majority were male patients. Additionally, due to the practical challenges implementing a new intervention, post-operative interviews were conducted at different timelines following surgery. This may have resulted in different descriptions of lived experiences.

The clinical efficacy and improvement in comorbidity symptoms and quality of life, as measured with objective markers, has been demonstrated for this cohort [9]. A strength of this study is its focus on experiences of subjective clinical efficacy regarding motor symptoms, non-motor symptoms and quality of life. As this was the first qualitative study on individuals' lived experiences following TS-DBS in this country and context, participants appreciated the opportunity to express subjective impressions and having 'voice' and 'visibility' that extended beyond motor symptom alleviation and surgical success. This contributes to a greater understanding of interventions incorporating principles of personalised care.

Future research

Future research would benefit from a more heterogenous sample recruited from different provincial clinics/movement disorder centres. Conducting interviews immediately pre- and post- DBS, and at intervals throughout the first two years post-DBS will potentially reflect a more comprehensive lived experience journey of the individual with TS following treatment with neurotherapy. Multiple perspective including that of family/carers and health professionals is an important area for future research and may contribute to aligning of perspectives of multiple role-players regarding changes and challenges experienced by individuals with TS. Furthermore, this will assist in developing neuropsychoeducation initiatives for families and carers.

Conclusion

This study depicts diverse and complex experiences, highlighting both the difficulties and transformations involved with TS and DBS treatment. Experiences of TS, hopefulness for change after DBS, the

eventual shift in identity and social relationships, embodiment of neurotechnology, all characterised this complex journey that participants endured. Some experiences showed that the process of adapting to this treatment is not without challenges, and continuous multidisciplinary team support and care for both patients and families are critical for achieving the best potential outcomes. While DBS may be an effective treatment for reduction in TS symptoms, findings suggest that the experience itself is complex and depends on compliance with treatment programmes after surgery. Individual characteristics such as gender may shape patient experiences pre- and post-operatively, and patients may experience changes in identity and social interaction after surgery. According to Gaille [32], DBS patients' lived experiences and involvement in forms of care are integral to determining the value and purpose of post-operative patient care. Further qualitative research is needed to disentangle the lived experiences of participants with TS and to explore how these are transformed following neurotherapeutic intervention. By identifying and addressing these gaps, future implementation of neurotherapeutic interventions such as DBS can contribute significantly to efficacious neurological and psychological outcomes in the African context.

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Author contributions

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Data availability statement

The data that support the findings of this study are available on request from the corresponding author.

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