


# “He’s Back so I’m Not Alone”: The Impact of Deep Brain Stimulation on Personality, Self, and Relationships in Parkinson’s Disease

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## Abstract

Deep brain stimulation (DBS) for Parkinson’s disease successfully alleviates motor symptoms, but unanticipated changes in personality, self, and relationships can occur. Little is known about how these nonmotor outcomes affect patients and families. We prospectively examined the experience and meaning of DBS-related changes in personality and self for patients and caregivers. In-depth, semi-structured interviews were conducted with 22 participants (11 patient–caregiver dyads) before and 9 months after DBS and analyzed using thematic analysis. We identified three themes present prior to DBS that reflected a time of *anticipation*, while three themes present after DBS reflected a process of *adjustment*. Participants noted both positive and negative personality changes, with some, but not all, attributing them to the stimulation. The risk of stimulation-related personality change should be weighed against the procedure’s motor benefits and considered in the context of disease- and medication-related personality changes. Clinical implications including perioperative education and follow-up management are discussed.

## Keywords

personality; self; identity; Parkinson’s disease; deep brain stimulation; caregivers; relationships; illness experience; interviews; qualitative analysis; qualitative semistructured; thematic analysis; South Eastern Australia

## Introduction

Deep brain stimulation (DBS) is a neurosurgical procedure used to treat severe movement disorders, primarily Parkinson’s disease (PD). DBS received Food and Drug Administration approval for PD in 2002 and more than 150,000 patients have since been implanted with devices (Medtronic, 2019). DBS can significantly improve motor symptoms associated with PD, such as bradykinesia, tremor, freezing, and increase functional independence (Deuschl et al., 2006). However, a variety of unanticipated psychosocial changes have been reported in some patients, including aggression, disinhibition, hypomania, hypersexuality, apathy, and impulsivity (Lewis et al., 2015; Pham et al., 2015; Romito et al., 2002). The terminology used to describe such changes in patients after DBS varies across research and clinical practice, including neuropsychiatric symptoms, neuropsychological consequences, psychiatric complications, behavioral issues, and adverse events (Thomson et al., 2019). To best explore a broad and inclusive range of patient experiences (i.e., in thinking, feeling, and behaving), we have chosen to examine *personality change*.

Patients have also experienced changes in how they perceive themselves and their body after DBS. Some feel “dehumanized” by the device and see it as an alien entity, whereas others accept it as part of their body and who they are (Agid et al., 2006; Gilbert et al., 2017). Cases of poor psychosocial adjustment following DBS have been documented, whereby patients struggle to adapt from being chronically ill to suddenly well (Baertschi et al., 2019; Bell et al., 2011). This is often referred to as the *burden of normality* (BoN; Wilson et al., 2001). Researchers have speculated on the potential for personality change and poor postoperative adjustment to

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negatively affect interpersonal relationships, particularly with spouses (Agid et al., 2006; Schüpbach et al., 2006). However, there is limited research on patient and caregiver perspectives on the causes of these outcomes and their significance.

Reports of undesirable personality changes and feelings of self-estrangement following DBS have prompted significant interest in the field of neuroethics. These changes have been widely debated according to various philosophical interpretations of identity and self (e.g., personal identity, autonomy, authenticity) (Baylis, 2013; Glannon, 2009; Kraemer, 2013). Some neuroethicists and clinicians have raised concerns about the potential sensationalizing and inflating of the putative effects of DBS on personality and related concepts (Gilbert et al., 2018). These include the tendency for articles to ignore, distort, or misrepresent empirical findings and that the alarmist discourse could produce unjustified fears that deter patients and families from pursuing a potentially beneficial treatment (Kubu et al., 2019). To address this sensationalism, firsthand empirical studies investigating the meaning and significance of DBS-related changes for patients and families are required. The role of related issues in the presentation of personality changes also need to be considered (e.g., prolonged impact of illness, expectations for DBS, adjustment to treatment outcome).

To achieve this, a prospective, in-depth qualitative approach involving both patients and caregivers is required. Standard psychometric personality measures are not designed to detect the types of changes associated with DBS, and there are limited reliable measures that examine complex concepts such as self and identity (Kubu et al., 2019; Lewis et al., 2015). Personality changes associated with DBS can be transient, remitting with stimulation reprogramming, and, therefore, may not be present at the exact time of assessment. Crucially, the meaning of what a given change in personality represents to a person, its impact on a person's life narrative, and sense of self is best understood using an open-ended, qualitative, and narrative-oriented approach. This has the advantage of reflecting the relational aspects of personal identity, as well as the limits of self-awareness and insight into one's own behavior (Barclay, 2000; Mead, 1934). Relational dynamics, including with spouses and close relatives, are generally self-shaping relationships (Overall et al., 2010) and have been shown to be affected following DBS (Agid et al., 2006). Patients can have limited insight into their changed behavior, with caregivers noticing changes patients themselves are unaware of or unconcerned with (Pham et al., 2015). Caregivers are also directly affected by the changed behavior, so their perspective provides additional insight into DBS' broader

relational and social impact (Haahr et al., 2013). With the exception of a phenomenological case study (Eatough & Shaw, 2017), qualitative research thus far has been primarily retrospective. This requires patients and caregivers to reflect on their preoperative and premorbid states months after surgery. Retrospective recall can be biased by current circumstances and interim events, leading to an inaccurate reflection of an individual's actual experience (Schacter et al., 2003). In taking a prospective, longitudinal approach, a nuanced psychosocial picture of the patient-caregiver dyad prior to DBS can be created and contrasted with post-DBS outcomes. Capturing patient and family voices highlights personal needs that can guide more patient-centered approaches to DBS clinical care (Eatough & Shaw, 2017; Hariz et al., 2016).

The purpose of the current study was to examine the significance and meaning of DBS-related changes in personality and self for patients and caregivers. In doing so, we addressed the following research questions:

**Research Question 1:** To what extent are patients and caregivers aware of the risk of DBS-related personality change?

**Research Question 2:** What, if any, changes in patient personality or sense of self are experienced following DBS?

**Research Question 3:** What do patients and caregivers consider the cause of such changes?

**Research Question 4:** What impact do these changes have on patients and caregivers?

**Research Question 5:** How is unintended personality change managed clinically?

This is the first study to conduct a *prospective*, qualitative analysis of both DBS patients with PD *and* their caregivers who addresses these issues.

## Method

A prospective qualitative study design was used to explore participants' perspectives, expectations, and experiences of DBS at significant time points (presurgery and postsurgery), with a particular focus on patients' personality and self. The term personality is often understood differently between psychological and sociological disciplines. Rather than restricting participants' responses, and our qualitative interpretation of them, to one framework or definition, we purposefully adopted the participants' own understanding of personality. Research ethics approval was obtained from the Monash University Human Research Ethics Committee (CF16/1888-2016000963) prior to conducting the study, and written informed consent was received from all participants.

## Participants

Purposive sampling was used to recruit individuals with PD preparing for DBS in the Melbourne, Victoria, region via neurologists specializing in movement disorders. Participants were eligible if they (a) had a diagnosis of PD; (b) were scheduled for DBS surgery; (c) were aged between 18 and 75 years; (d) were able to provide informed consent; and (e) had a caregiver (spouse, family member providing daily support) who was willing to participate. Exclusion criteria for patients included dementia and severe psychiatric or additional neurological disorders (typical DBS contraindications assessed by the medical team during the selection process). Eleven patient–caregiver dyads preparing for DBS agreed to participate. Patients were seven men and four women, ranging from 45 to 73 years of age. Six were employed and five had retired. Time since PD diagnosis ranged from 3 to 12 years. Caregivers were two men and nine women, ranging from 51 to 69 years of age. They included spouses ( $n = 9$ ), parents ( $n = 1$ ), and children ( $n = 1$ ) and had known the patient for 29 to 51 years (additional demographic information in Supplemental File). Two patient–caregiver dyads did not complete follow-up interviews: one due to the patient ultimately deciding not to undergo DBS and the second due to health issues. One dyad completed two follow-up interviews: the first 9 months after an initially unsuccessful surgery due to infection and the second 9 months after a subsequent successful reimplantation. The subthalamic nucleus (STN) was the implantation site for all patients, except one with globus pallidus. Small samples are suited to longitudinal interview-based studies of this kind, as they require the fostering of positive, ongoing relationships with participants and produce an abundance of rich, complex data (Crouch & McKenzie, 2006). Data saturation was achieved at each time point, which suggests that the sample size was appropriate.

## Procedure

Audio-recorded, semi-structured interviews were conducted with participants between May 2017 and January 2019. Pilot-tested interview schedules were used, one for each participant type (patient/caregiver) and time point (pre/postsurgery; see Supplemental File). All interviews were conducted by Cassandra Thomson. Separate interviews were conducted with patients and caregivers to allow for open discussion and discrepant perspectives (Mellor et al., 2013). Presurgery interviews were conducted for 3 to 25 days ( $M = 13$ ) prior to surgery. Follow-up interviews were conducted approximately 9 months postsurgery. Interviews were conducted in-person or via telephone/video-conference for participants

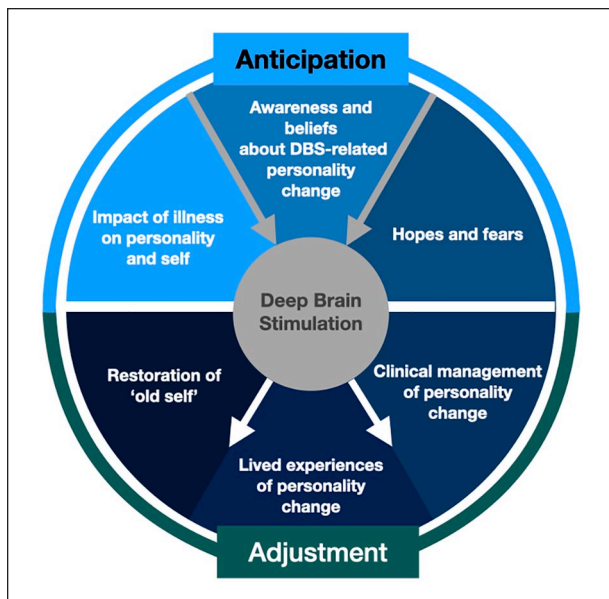
who lived remotely or interstate. Interviews ranged in length from 30 to 120 minutes ( $M = 42$ ), with a total of 30-hour recorded data collected. The interviewer maintained field notes and regularly debriefed with coauthors. These discussions were influenced by backgrounds in neuropsychology, psychology, qualitative research, and neuroethics. Audio-recordings were transcribed verbatim by a professional transcription service and reviewed for accuracy by the research team. Transcripts were not returned to participants for corrections or comments.

## Data Analysis

Interviews were analyzed using a thematic analysis approach whereby patterns of meaning are examined and identified inductively within the data (Braun & Clarke, 2006). This approach is suited to studies that aim to elucidate participants' perceptions, feelings, and experiences. Thematic analysis also allows similarities and differences across participant groups and time points to be highlighted (e.g., patients/caregivers, before/after surgery). The analysis was conducted within a realist paradigm that assumes the language used by participants reflects the reality of their experiences and meanings (Braun & Clarke, 2006). The analysis process commenced with data immersion involving listening to audio-recordings and reading transcripts several times. Initial reflections were recorded in margin notes. An initial list of codes was continually revised, condensed, and arranged into meaningful groups that reflected the emerging primary and secondary themes. Summaries for each interview from every dyad were also created, highlighting similarities and differences in perspectives across participants and time points. Cross-coding was conducted on three sets of patient–caregiver interviews. The coders compared coding approaches, and minor disagreements were discussed until a consensus was reached and final coding structure was developed. This structure was then applied across all interviews, with minor adjustments made following feedback from coauthors.

## Results

Themes identified prior to surgery reflected a time of *anticipation*. These interviews contained a mixture of hope, anxiety, fear (“I’m scared”), and eagerness (“bring it on!”) centered around the impending surgery. Overarching this was a sense of uncertainty for the outcomes of this key event and its implications for the future. Following DBS, participants had moved beyond the surgical event and were now in a process of *adjustment*, to the DBS itself, but within the broader context of ongoing adjustment to chronic illness. Interview questions focused on participants' experience with DBS,



**Figure 1.** Thematic analysis visualization.  
Note. DBS = deep brain stimulation.

but responses were considered in this broader context of psychological, social, and physical adjustment to chronic illness (Moss-Morris, 2013) for both patients and caregivers. As questions surrounding personality change were guided by participants' own interpretations, responses included nontraditional aspects, such as changes in day-to-day routine, mood, self-confidence, and bodily functioning. Results focus primarily on personality change, as this topic held relevance for participants and produced the most responses. Themes identified during the time of anticipation and process of adjustment are displayed in Figure 1.

### Anticipation Themes

**Impact of illness on personality and self.** Throughout the interviews, participants described how the patient's personality and sense of self had been affected or changed by their illness. Many felt that PD sat incongruently to important features of their self-concept and inhibited their ability to express their true personality. Examples include an active, adventurous person being hampered by fatigue and amotivation; a highly social person becoming withdrawn and apathetic; and a fiercely independent person having to rely and depend on others for support.

How PD affected expression of the patient's personality and self was varied, with physical, mobility, cognitive, and speech deficits all affecting. Participants commonly stated that the illness had diminished the patient's self-confidence and that they regularly experienced feelings of anxiety, angst, and embarrassment, especially in social settings.

I find that Parkinson's in particular undermines your self-belief and personal confidence. All those sorts of things. The Parkinson's runs sort of counter to that . . . people see me sort of shuffling around and knocking over the bloody water jug in restaurants and not being able to open doors. (Patient [P])

This reduced self-confidence appeared linked to patients' perceived lack of personal control over their symptoms (e.g., freezing, excessive sweating, motor fluctuations, becoming dyskinetic) and concerns about how others may perceive and misinterpret their symptoms (e.g., due to alcoholism or a stroke, or are "cuckoo").

Patients and caregivers discussed problematic changes that had occurred since developing PD, either as a result of medication or the disease itself. These included the development of depression, anxiety, apathy, amotivation, impulsiveness, cautiousness, impaired decision-making, and impulse control disorders (ICDs; e.g., compulsive gambling, shopping, eating, hypersexuality, and hobbyism). The emotional impact of these changes spanned from minor inconveniences that participants stoically took in their stride to more frightening and distressing transformations. For patients who had experienced notable cognitive or neuropsychiatric changes (e.g., ICDs, medication-induced psychosis), spouses conveyed feelings of estrangement from the person they had married and known for decades:

This man, this personality change he's gone through, it's crazy. It's not—he's not the man I married. He's definitely not the man I married. He's changed so much. If that's just part and parcel of Parkinson's, I guess? (Caregiver [C], discussing ICDs)

I had a whole range of behavioral problems . . . a whole raft of really, really odd stuff . . . [spouse] tells me I was really scary. That really sort of upset me to think that we've been married . . . a long time and when someone tells you that you've scared them . . . She said that often I've got the capacity to—only since the Parkinson's stuff—to scare people. (P, discussing medication-induced psychosis)

Participants off-set these undesirable changes by highlighting positive aspects of the patient that were robust and unwavering, despite their illness, such as their positive attitude, strong character, and kind "*do anything for you*" nature.

**Awareness and beliefs about DBS-related personality change.** Many participants reported they were unaware of the risk of potential changes in personality, mood, or behavior following DBS. For the few who were, the kinds of changes they described included depression, compulsivity, increased emotion, decreased empathy/compassion, and generally "wanting to do things differently."

Awareness of these changes had occasionally come through information provided by their DBS team, but more often other sources, such as internet pages, journal articles, or other DBS patients' personal experiences, for example, losing "your sense of empathy" (P). A few participants were aware of some PD medications being associated with certain changes, including increased interest in gambling and alcohol, but were unaware of a relationship with DBS.

Certainly tablet-related. They talked about things to look out for in terms of drinking, gambling, and things . . . but yeah, not particularly after the surgery. (P)

When participants were asked if they thought DBS could change who they are/who the patient is, a few reflected it could, given the mystery surrounding how the brain functions and multiple brain regions possibly being affected. Some patients described the effects of medication on their thinking and feeling, leading them to believe another form of treatment could temporarily change who they are.

I've always been amazed that these tiny drugs can affect—have cognitive effects as well as physical. You can break a tiny one in half . . . and it can make a difference. (P)

Most patients ( $n = 9$ ) had undergone psychiatric and neuropsychological assessments as part of the procedure screening process. Based on assessment feedback, some patients understood themselves to be in good cognitive and psychological health (i.e., cognitively intact with an absence of depression or problem gambling). This feedback encouraged a sense of self-efficacy in these patients who felt they were unlikely to experience any future personality change. A stable demeanor, "strong personality," and positive outlook were also suggested as reasons for a reduced risk of personality change. One caregiver felt DBS would not change their spouse's personality, as that was not the intended purpose of the procedure:

[DBS is] there to stimulate for [in place of] drugs, not to stimulate his personality or change him into a monster or anything. So, no, I don't think anything about him is going to change except what it's meant to do. (C)

When asked about how long they believed a change in personality could last, many expressed uncertainty. Others felt it would be fixable and could be addressed by their treating doctor adjusting the stimulator or changes to medication (e.g., treating low mood with an antidepressant). Turning the device off completely was considered a means by which any undesirable changes could be ceased and a reassurance. Others felt proceeding with the procedure could have more permanent consequences, depending on whether the intervention was successful or not.

That's one of the concerns that [spouse] has . . . once we go down this path, you can't go back. In fact, [neurologist] said that. He said . . . "you'll change, whether it's for better or worse," he said "you won't be the same person." (P)

*Hopes and fears.* Undesirable changes in patient personality following DBS were a concern for some, particularly those who had already experienced significant personality changes as a result of disease pathology or medication (e.g., ICDs, medication-induced psychosis). These participants, particularly caregivers, expressed fears that these behaviors could be exacerbated or would reemerge following DBS.

When you read up on the deep brain stimulation, it says it can actually make them [ICDs] worse. I'm thinking, oh my God, how much worse can it get?! (C)

In cases where these fears had been fully discussed with the DBS team, they were sufficiently allayed for the pair to feel comfortable proceeding with the procedure.

Participants were asked what aspects of themselves/their close-other they were unwilling to lose or exchange for improvements in motor symptoms. Patients reflected on their socially desirable qualities, such as being caring, positive, reliable, and trustworthy. They also considered the negative consequences that could arise if these were to change, such as becoming isolated from their family and friends or disrupting their successful relationships with workplace colleagues and clients.

It's just me and how I treat the people around me. They're all very fond of me . . . I don't want to lose that. I have so many friends around me because I'm a caring person. (P)

Caregivers expressed concerns their close-other could lose their defining characteristics (e.g., willingness to "take life in both hands" or "very placid" temperament). The extent of the change was also important, as some felt they could accept and adjust to minor negative changes, but not dramatic or serious changes (e.g., becoming violent).

I wouldn't want to see any kind of change that was too dramatic . . . if he was to become really outgoing or really inward or really selfish or—I wouldn't want any of those in exchange for his physical capabilities. (C)

While undesirable personality changes were a concern, perioperative issues tended to be more pressing. These included anxiety about ceasing medication prior to surgery, adverse events occurring during surgery, uncertainty about postoperative care (e.g., changing bandages), esthetic concerns (e.g., shaving hair, scarring on scalp),

and ultimately whether the procedure would be successful or not.

With these concerns came hopes for desirable personality change with DBS, specifically a restoration of qualities lost through the disease or to simply go “back to normal.” Some hoped DBS would give them the “freedom and energy” to express their true self and act in the world in a way they value. Particular areas participants hoped to see change were mood (be a “happy person” not “miserable”), demeanor (“fun-loving” not “easily frustrated”), and social engagement and connection with others (take “more of the world in” not just focus on illness).

### Adjustment Themes

**Restoration of the “old self.”** Following surgery, several patients did experience a restored sense of premorbid self postsurgery, that was often referred to as their “old self.” Improvements in energy, mood, motivation, cognition, and mobility contributed to the restoration. This allowed them to express their true self in ways the illness had hindered. This sense of a restored “old self” was exclusive to patients who experienced good clinical outcomes with DBS. One patient who had their DBS removed due to infection was able to reflect and contrast their experiences of being with and without the device, including the certainty and control DBS provided:

I certainly was a different person [with DBS], like going back—it was the old me rather than what we’ve got now . . . yeah, I just had more energy, more up and go, not tied down to a timeline so to speak, because I know at certain times during the day I go into an off period, so therefore I alter my life around that. (P)

Caregivers of patients who felt their “old self” had been restored shared this perspective, including how their mood, motivation, and behavior reflected the person they had known prior to PD. Feeling the patient was back “to normal” led one caregiver to refer to the disease in the past tense, despite knowledge of its ongoing presence:

When she had the Parkinson’s—she used to worry a lot. She used to be really down. Now she’s sort of the old [spouse] I know. She laughs at my jokes, even how corny they are . . . yeah so, no, she’s a much happier person. (C)

These couples appeared to return to a more equitable relationship dynamic. Caregiver burden was reduced, with increased freedom to enjoy activities independently and security leaving their loved one alone overnight. Restoration of the “old self” was associated with a sense of relief for family and friends and reestablished unity for spouses.

Any work colleagues or friends of his [say], “it’s great to see the old [patient name] back, we were really worried there for a little while” . . . now I feel like I’m not totally, you know, he’s back so I’m not alone again. So that’s good. (C)

Caregivers focused more on external features, such as the patient’s physicality and regained facial animation. Patients tended to only become aware of these improvements from observer comments. While positive comments were mostly well received by patients, one expressed frustration that these often did not reflect their internal experience:

When you see people, they go “oh gee, you’re looking well.” Yeah okay, I might be looking well, but I . . . don’t feel that well. So, I wish people wouldn’t say that . . . sometimes that doesn’t necessarily match who you are or what you are or how you feel at that particular time . . . because, as you know, Parkinson’s doesn’t only affect movement, it affects other parts of the body. (P)

The alleviation of debilitating symptoms provided patients with a restored sense of self-confidence. Alleviated tremor or dyskinesia was associated with reduced feelings of anxiety and embarrassment (for both patients and caregivers), leading to greater socialization.

[DBS] gives me my self-confidence. If you don’t feel confident, because you got shakes . . . because you think people think you’re an alcoholic or something, it knocks you about a bit. So that, having that cleared up makes a big difference. (P)

For a few, increased self-confidence emerged from an internal experience of improved cognitive clarity and alertness, facilitating better engagement and connection with others.

Increased certainty and symptom control, compared with medication alone, was noted as providing confidence to patients to be more independent and perform activities aligned with their values and prior selves (e.g., attending music concerts, hosting dinner parties). In contrast, those with less favorable outcomes reported a sustained experience of negative self-confidence. A key feature of these experiences was problems with speech (slurring, rapid speech, low volume, articulation difficulty, and stuttering).

I’ve never had a stutter in my entire life, ever. It was only post-operation . . . Basically, my self—confidence has gone out the window and a lot of it is due to the bloody Parkinson’s, the—this, having the stammer. (P)

While some participants were uncertain, others were confident speech issues were an unintended stimulation side-effect due to their immediate onset postsurgery or

responsiveness to stimulation adjustment. The development of postoperative issues with mobility, balance, and mood also affected confidence.

It would be good to know [be close to] some of my great grandkids . . . now I daren't. You know, I don't feel confident enough like I did before. (P)

*Lived experiences of personality change.* In the nine patients followed up after DBS, personality changes experienced varied from positive mood changes ( $n = 4$ , e.g., being happier, more lighthearted, more euphoric) to negative mood changes (e.g., more depressed [ $n = 2$ ]; angry, frustrated, grumpy, irritable [ $n = 5$ ]), changes in thinking and cognition (alert, quicker, clearer [ $n = 2$ ]; more confused, slower, forgetful [ $n = 3$ ]), and changes in behavior and interpersonal style (e.g., more assertive, forthright [ $n = 2$ ]; fixated, obsessive [ $n = 2$ ]; impulsive, impatient [ $n = 3$ ]; demanding, disinhibited, insensitive [ $n = 1$ ]; withdrawn [ $n = 3$ ]). Patients described exactly how they felt different from their “normal” or usual self.

At the moment, [I'm] slightly more euphoric than normal. That was one of the side effects of . . . one of the changes. (P)

I'm probably more angry than I used to . . . I get a bit agro towards [spouse] . . . just suddenly started—when I can't move—bang! I get cranky quick, agro. (P)

I've always been quite patient, but now . . . there are times when I've been really stubborn and times when I want to do something . . . then I have to go now; I have to do it now. (P)

Participants identified a wide variety of potential causes for the changes experienced, including (a) the direct effect of stimulation within the brain, (b) the indirect effect of stimulation through alleviating debilitating symptoms or new side-effects, (c) medication adjustments, (d) frustration with residual symptoms and unmet expectations, (e) comorbidities and additional medical procedures, and (f) the ongoing progression of PD. Participants displayed a nuanced understanding of the potential influence of one or multiple factors and occasionally attributed different changes to different causes.

She was always a bit feisty beforehand, but now . . . she does get very defensive very quickly . . . It could be a mixture I think, of the DBS and muddling with her brain, and the fact that her Parkinson's has progressed, and the [cancer related] operation. (C)

Whether [the cognitive changes] were just marred by the movement prior to and you concentrate just on one thing and forget about the others . . . because we concentrated so much on the movement and trying to help with that. (C)

Pairs could describe the same observed change, but draw different causal conclusions, with patients more likely to consider the stimulation effect of DBS as the causal factor.

I think I fly off the handle probably a bit more than I used to . . . I put it down to the DBS, because it's more abrupt. Parkinson's is very gradual, well with me anyway, very gradual, takes six months for something to develop. (P)

He gets very frustrated and exasperated. It's not like [him], he was very placid beforehand . . . I'm not used to him being like that and being so expressive . . . It could be the Parkinson's too, I think. Because it's still in the background . . . I know [another person with PD] . . . he was a very placid person too. He got very exasperated . . . So, I think that's something that probably happens. It's not necessarily the DBS. (C)

Participants described transient personality or behavioral changes that had occurred during the previous 9 months and since resolved. Two patients experienced postoperative confusion and disorientation that manifested in anxiety, emotional lability, hallucinations, vivid dreams, disturbed sleep, neediness, and dependency on caregiver. These resolved with time and were attributed to the anesthetic or the implant.

I thought it might have been . . . the fact that, you know, there's a foreign object in my brain. I was thinking that maybe that just disturbed things a bit. (P)

Two other patients experienced a postoperative “high” where they were elated with their surgical outcome, whereas caregivers shared a more modest view. One patient was able to reflect on this period as a “false high,” whereas the other struggled to come to terms with never being as good as they were in hospital. Some transient changes were considered stimulation dependent due to their responsiveness to adjustment of stimulation parameters and included uncontrollable laughter and erratic, impulsive behavior.

He talked incessantly, non-stop and just kept swapping from topic to topic to topic . . . He'd just ring people up and go, “oh, I'll pick you up in 10 minutes” . . . but the neurologist just changed channels or whatever and that disappeared . . . Apparently, he was on a high with it. It was like being on drugs and stuff. (C)

Participants also described more sustained changes they had noticed in the months following the surgery and had continued until the time of interview. Sustained changes were often attributed to PD-related cognitive decline (e.g., poor engagement in conversation, verbal disinhibition). However, a few patients felt changes were associated with

the stimulation effect (e.g., irritability, assertiveness), but had not attempted to address them as they were not considered overly problematic or were seen as a trade-off for improvements in other areas.

There was high consistency in the types of changes described within dyads (e.g., irritability, low self-confidence, positive or negative mood changes), although some caregivers reported changes their loved one did not. Caregiver comments suggest this was due to the patient having limited insight into their behavior, either in the context of a brief stimulation-related episode ( $n = 1$ ) or progressive cognitive decline ( $n = 2$ ). One patient described past behaviors where they appeared to have poor insight at the time, but following discussion with their caregiver, came to recognize it as uncharacteristic or unusual.

I look back on some of the things that I suggested and said, and they were ridiculous! Like buy heaters when we don't need heaters [laughs]. (P)

When exploring the impact of personality changes following DBS, transient experiences such as postoperative confusion and erratic, impulsive behaviors were particularly concerning for caregivers and raised momentary doubts about the decision to undergo DBS.

It was actually quite scary, his behaviour and stuff was quite erratic . . . [I'm] thinking is this what the future basically is with this person? Have we done the right thing? . . . because he was a little bit awkward to live with for a little while there. (C)

In such instances, a resolution of the changed behavior was a relief for the caregiver and family, but this was not always the patient's experience.

Whereas for him, he said it was terrible, because it was like being pulled off your medication . . . and being withdrawn from it, because he felt great. (C)

The patient did not raise this particular experience in the interview, and it is uncertain whether this was due to limited recall or insight, or due to feelings of shame or embarrassment. Another patient who experienced more persistent, yet minor, changes (e.g., increased assertiveness, stubbornness) expressed some embarrassment when reflecting on their changed behavior in a social community setting:

[In] a committee of 12, when I'd say "well, come on, what are we going to do?" We'll go around the table and everyone says "n" [laughs] and [I say] "yes." Okay . . . work that out . . . I suppose a degree of carelessness in that role, and also a degree of self-focused . . . not conducive to having discussions about things. (P)

This was particularly noticeable when contrasted with comments from the same patient's previous interview where a comparable scenario was described, but with the patient playing a more passive role:

I'm chairman of the committee, so I can let everybody else make the decisions, I just sit back and say "okay then, that's great, go with it." We have a great committee who always produce a really good result. That's really good for me. It makes me feel great when it happens. (P)

The three reported instances of presumed stimulation-related personality change appeared to have brief or minor social implications, with the caregiver relationship mostly affected. In response, some caregivers demonstrated capacity to accept and integrate minor changes into their lives. For example, one adjusted to an increase in compulsiveness by indulging their spouse's innocuous desires (e.g., getting an ice-cream), whereas being firmer and taking more time to discuss unreasonable requests (e.g., taking a spontaneous overseas holiday).

We just have more discussions I think about why or why not, particularly with money . . . it's probably just explaining things a little bit more to him. (C)

Caregivers were also able to adapt to changes they had initially feared (e.g., spouse no longer being placid). Other persistent changes, such as apathy and social withdrawal, could be more difficult for spouses who wanted to share activities and experiences as a couple, especially as they enter retirement. Irritability, frustration, and anger were also a challenge, but how caregivers responded differed and appeared influenced by their preexisting relationship.

I wouldn't say adjusted to [laughs]. I just tell him "don't speak to me like that!." Not in a nasty way . . . joke in a way. Because I know he doesn't mean it, he just gets a bit frustrated with himself because he gets aches and pains. (C)

I argue back, don't worry about that. I argue right back at him, I think just because you've got Parkinson's disease, you're not getting away with this. (C)

For one pair, ICDs were a pre-DBS relationship stressor with the caregiver expressing concern DBS could exacerbate them. After DBS, the caregiver felt there had been no increase, nor had DBS produced significant treatment effects beyond medication reduction.

I don't think it's made it any better or worse, I really don't think it's changed anything, to be honest, except his meds are down . . . but as far as the personality and [his] behaviors, they haven't changed. (C)



Notable cognitive changes, whether neuropathological or stimulation related, had a more pronounced negative relational impact. Cognitive decline signaled a progressive loss of who the patient was and grief for family and friends. The nature of these relationships also tended to change, with caregivers taking on more of a nurse role. Caregiver burden was higher in these instances and compounded by the fact caregivers themselves were experiencing serious medical issues. While some personality changes were considered frightening or challenging, they tended to be low on participants' list of concerns. Issues such as balance and falls were a higher priority and associated with greater levels of anxiety, particularly for caregivers.

Overall, questions about personality change were easily answered by participants, with most able to identify and describe various changes. Participants occasionally had difficulty articulating exactly what they observed or experienced, and sometimes made contradictory statements about whether personality change had occurred:

[It] hasn't changed his personality . . . but he's now got a little bit more assertiveness . . . or—not argumentative [pause]. There is a change and I can't quite pinpoint how I would verbalize it . . . Stand up for himself is not right either . . . he's always been pretty passive so it's quite funny when he'll just say “no, I don't think that's right” . . . yeah, so there is a slight, you might actually say personality change (C)

In comparison with questions about personality change, questions about whether the patient felt like themselves after DBS were met with much sparser and hesitant responses. Most indicated that they did feel like themselves, despite previous discussion around the ways in which they or their personality had changed. Some participants felt they or their loved one was only partially themselves now, but what they had lost was largely attributed to PD, not DBS.

*Clinical management of personality changes.* There was significant variability in participants' reporting of clinician enquiry about changes in mood, personality, or behavior after DBS. There appeared no link between participants' responses and the clinicians involved in their care or where surgery was performed. Those who reported not being asked about it felt they could raise it with their treating team or contact them if needed. Some participants vaguely recalled conversations about personality change, but were uncertain who initiated it. In these cases, no attempts were made to address the changes as either the pair considered them “nothing major” or the clinician attributed them to PD rather than DBS.

We probably told them [DBS clinicians], but it doesn't ever seem to be much of a problem. Like it's not that it's not taken

seriously, but it's like “oh well, that's Parkinson's,” that's one of the Parkinson's things and it's like “move on” . . . no, they're only concerned if there's something big or real or something they can change. (C)

For patients living far from medical specialists, the number of consultations and degree of clinical contact they had appeared limited compared with metropolitan patients. Limited clinical contact and time-pressured appointments were reasons given for their specialist not raising the topic of personality change.

He [neurologist] hasn't asked anything really . . . most of the appointment takes up getting the meds sorted and getting the machine sorted. (C)

Caregivers felt their feedback was generally encouraged in appointments, but could not always attend due to full-time work or other commitments. One caregiver noted the importance of attending so they could respond to clinician enquiries and had reported impulsive-compulsive type changes they had witnessed that their spouse did not raise:

That's why I do like to go to the appointments with him when I can, because . . . then you give your point of view. That's how this popped up the first time, because he would have said “no, I'm fine. I'm fine.” I said “well, actually . . .” [laughs], you know? Because otherwise—yeah, he [neurologist] would have never have known. (C)

In this case, the behaviors swiftly ameliorated following stimulation adjustment. The experience left the caregiver confident they could detect uncharacteristic behavior in the future and gave them a sense of relief that such behavior would be transient. Still, a desire for more preoperative information around these types of changes was expressed. It was believed that this information would better prepare the caregivers for potential personality change, provide an explanation for any changes, and provide a rationale for clinicians' line of questioning during appointments.

Interviewer: Are there things you would have liked to have known beforehand, before the surgery or maybe had emphasized more?

Definitely the behaviour side of it . . . because that was really quite scary . . . he would just go! . . . whatever he'd thought he'd just go and do it . . . We had no understanding that could just be changed by changing the controls . . . So I think they need to tell people that, because if it had gone on and just let him do whatever . . . Well, I wondered why—every time you go to a neurologist appointment, they'd ask you “oh, is there any change in behaviour?” . . . gambling, sort of, alcohol-type behavior . . . I'm going “no” . . . then when that happened . . . “oh, now I know why you ask that all the time!” (C)

For caregivers of patients with cognitive issues, allied health professionals assisted them with communication of corrective feedback that was often challenging due to patient personality changes, such as impulsivity or stubbornness.

Interviewer: Has it been helpful going to the movement disorders clinic?

It was, because it wasn't just me saying it to [her], this is how you're supposed to be getting in and out of a chair. It was someone else, and she was just reiterating and giving more hints. (C)

Caregivers of patients with cognitive issues and poor DBS outcomes experienced increased burden. These individuals highlighted the value of family and social support to manage these demands (e.g., overnight stays, getting to appointments) and importance of respite services to focus on their own health concerns. For patients experiencing depression or disappointment with their DBS outcome, opportunities to talk with other individuals with PD or DBS helped them feel connected and understood, even if their experiences differed. These connections were often facilitated through PD community groups.

## Discussion

Little is known about the significance of personality change following DBS for patients and families, nor their understanding of these potential changes prior to surgery. How the procedure affects patients' sense of self has been widely debated in the philosophical neuroethics literature (Gilbert et al., 2018), but few studies have directly investigated the meaning and importance of such changes for the patients themselves. This prospective examination of the DBS lived experience provides unique insights into these issues and raises a number of important points for consideration in DBS clinical practice.

### *Significance and Meaning of DBS-Related Personality Change*

Before exploring the effects of DBS on patient personality and sense of self, it is necessary to consider the preceding and ongoing impact of illness. Across interviews, both prior to and following DBS, PD was generally perceived as having a negative impact on patient personality and self-concept. Although some patients found positives from their illness (e.g., spending more time with family), none felt it had positively influenced their personality. This aligns with preliminary findings of another PD sample of DBS patients, where many reported significant,

largely negative, personality changes due to their illness (Kubu et al., 2019). When reflecting on their most-valued personality characteristics, patients expressed a diminution of these over the course of their illness (Kubu et al., 2019). Patients reported fewer changes in personality after DBS, and those they reported were largely positive. Similarly, the current sample reported a mix of positive and negative personality changes after DBS, while illness-related changes appeared to have a greater, more pervasive, and distressing impact. This does not suggest that significant and distressing changes related to DBS do not occur, as these have been reported elsewhere (Mosley et al., 2019; Romito et al., 2002). Rather, it highlights features of the DBS experience often overlooked in the conceptual neuroethics literature. That is, patients and families are entering it from a preexisting context of illness-related change and that DBS can positively affect patients' personality and self-concept. We found that a positive impact on personality and self was highly connected with a good clinical outcome. Rates of positive clinical outcomes should continue to improve with promising developments in DBS such as the identification of target-specific biomarkers (Sinclair et al., 2019), improved prediction of neuropsychiatric outcomes with lead location (Mosley et al., 2018), and closed-loop DBS systems (Krack et al., 2019).

Participants identified numerous ways they believed DBS had contributed to personality change, either in a transient or sustained sense. These changes did not result in the patient feeling they were now an entirely different person, but were incorporated into their self-concept. In another qualitative study, patients with PD reported no change in identity after STN-DBS, despite experiencing significant neuropsychiatric symptoms (Mosley et al., 2019). Once recovered, these radical changes appeared integrated into patients' autobiographical narrative. The authors suggested participant comments reflected an essentialist core self that PD had suppressed and which DBS had released to varying degrees. Much like the restored "old self," others have noted patients feeling more like their authentic "true self" after DBS (Schüpbach & Agid, 2008). In contrast, some have felt unlike themselves after DBS, and these experiences have been described in terms of alienation and self-estrangement. When discussing authenticity and alienation, Kraemer (2013) described two outcomes following DBS. First, that "DBS could threaten authenticity" (p. 484) with the patient feeling and acting unlike themselves, or second, that PD could be seen as a time of alienation, with DBS bringing them closer to authenticity. The latter resonates with our sample's experiences, with neuropathological changes and/or medication side-effects leading patients to feel and act unlike themselves, potentially to the degree their caregiver feels they no longer recognize them (Toms

et al., 2015). Differential abilities of patients to integrate changes (positive or negative) into their self-concept could be explained by varying levels of coping, resilience, and ability to adjust narrative to existential changes, as well as support to do so.

**Self-estrangement, autonomy, and control.** The notion of self-estrangement can be applied to patients' relationship with their illness, although it has typically been used to describe patients' postoperative experiences. In the current sample, illness-related self-estrangement appeared to be buffered in those displaying cognitive and behavioral factors associated with adaptive adjustment to chronic illness (e.g., benefit finding, optimism, problem-focused strategies, and engaging in good health behaviors) (Gardenhire et al., 2019). However, it was exacerbated in those who displayed maladaptive approaches (e.g., wishful thinking, helplessness, coping through avoidance; Dekker & de Groot, 2016; Moss-Morris, 2013). The introduction of DBS appeared to play either a restorative or a deteriorative role in levels of self-estrangement. The direction of this role was influenced by the perceived success of the procedure and the development of unanticipated side-effects (e.g., speech, balance issues). This direction also had the potential to shift depending on health status and treatment decisions (e.g., adjustments to stimulation parameters and medication, implant removal/reimplantation, microlesion "honeymoon" effect). Gilbert et al. (2017) previously described the qualitative nature of self-estrangement after DBS as restorative and deteriorative, with restorative reports characterized by an excessive perception of capacity (e.g., physical capabilities) and deteriorative characterized by a perceived loss of control. In the present study, restorative changes were largely perceived as a return to equilibrium disrupted by illness, rather than an excessive perception of capacity. In a deteriorative sense, some patients may have perceived personality changes and uncharacteristic behavior as a loss of control, but equally, perceived improved physical capabilities as regained control. These multifaceted responses to treatment, in addition to patients only experiencing minor or transient stimulation-related personality changes, may explain why none felt DBS had fundamentally changed them.

Perceived control was relevant to patients both prior to and after DBS and was important for determining how much they felt like their "true self." This is unsurprising, given the fundamental role of autonomy in the construction of one's identity (Ryan & Deci, 2000). PD had only a diminutive effect on patients' feelings of control, whereas DBS had the potential to both increase control (e.g., through greater predictability and flexibility managing motor symptoms) or *further* decrease control (e.g., through poor speech production, unstable balance, and

uncharacteristic behavior), echoing the pattern seen with personality. Improvements in perceived control have been documented in other PD DBS samples. Kubu et al. (2017) asked patients prior to DBS to identify their personal top symptom and behavioral goal, with a subjective rating of their perceived control over these. DBS significantly improved control over these personally identified symptoms and goals (e.g., with relationships, hobbies, and work particularly important) and patients' perception of control also improved. Mixed experiences have been reported in other samples. In their sample of STN-DBS patients, Mosley et al. (2019) described variable perceptions of control in relation to significant neuropsychiatric symptoms patients experienced (e.g., ICDs, irritability, aggression, dangerous driving). Some felt a loss of autonomy, due to their actions being out of keeping with their usual behavior and values. Others actively sought to change their mood with higher stimulation levels, thereby using DBS as a tool to exert control albeit in a way others deemed problematic. Mosley and colleagues' sample was selected for their significant neuropsychiatric side-effects and represent the "most severe end of the spectrum" (p.13). In selecting patients preoperatively, our sample experienced less dramatic side-effects (speech, balance, cognitive issues) that resulted in reduced levels of autonomy and control. These findings support previous studies which have shown how physical control affects sense of self-efficacy, autonomy, and control (Racine et al., 2013). From an experiential perspective, autonomy (as self-governance) is not clearly separated from physical independence and mobility. In standard PD care, promoting self-efficacy, control, and mastery is crucial, whether it be through adopting a healthy lifestyle, engaging in therapies (physio, speech, music), or developing hobbies (Gardenhire et al., 2019). Physical and sensory integrating activities in particular are recommended for the process of *preserving self* in PD (Vann-Ward et al., 2017).

**Individual and relationship adjustment.** Self-efficacy and control are important features of patient care and adjustment to any chronic illness (Moss-Morris, 2013). Given the complexity of symptoms and treatment outcomes in PD, multidisciplinary input is often recommended to support both the patient and family system (Hodgson et al., 2004) and promote positive psychosocial adjustment (Baertschi et al., 2019). DBS is only able to address a limited selection of the diverse symptoms experienced by patients with PD. As a result, patients will generally be left with unresolved symptoms following DBS, in addition to any undesirable side-effects. For this reason, the "burden of normality" phenomenon may not apply to PD DBS patients as previously proposed (Gilbert, 2012). BoN was originally used to describe the poor psychosocial adjustment witnessed in patients relieved of chronic

epilepsy following temporal lobectomy (Wilson et al., 2001). Despite being effectively cured, these patients experienced difficulty with social and vocational reintegration, to the dismay of those around them. In the current sample, one pair reflected on how the patient's post-DBS experience failed to match the perceptions of those around them (family, friends, and doctor), sharing some similarities with a BoN response to treatment. The patient, however, emphasized the ongoing impact of symptoms unaddressed by DBS that leaves it far from a cure. Others have recognized that the progressive nature of PD leaves it difficult to determine what underlies post-operative maladjustment (Baertschi et al., 2019). Despite differences in etiology and symptomatology, the multidisciplinary rehabilitation approach advocated for in the case of temporal lobectomy is also relevant to patients' psychosocial adjustment following DBS.

Concerns about the negative impact of DBS in spousal relationships have been raised ever since Agid and colleagues (2006) reported 65% of their patients with partners experienced a conjugal crisis within 2 years of undergoing DBS. Stimulation-related personality changes were considered one possible contributing factor, in addition to changes in relationship dynamics, the stress of undergoing neurosurgery, and the intervention's failure to meet expectations. Here, it appeared preexisting relationship issues were exacerbated by the procedure. In our prospective study, we found relationship quality tended to remain fairly consistent longitudinally, regardless of whether undesirable personality changes developed.

A poor clinical outcome and progressive cognitive decline were more challenging aspects for pairs, regardless of relationship type (spousal, parent/child). In a previous qualitative investigation of cognitive impairment in PD, two prominent grieving themes were described: a *loss of sense of self* for patients and a *loss of partner* for spouses (Lawson et al., 2018). While patients attempt to maintain a sense of self and valued identity, spouses process the progressive loss of their partner and relationship (Toms et al., 2015). Advanced cognitive impairment in PD is associated with troubling personality changes and poor caregiver quality of life, with spouses struggling to maintain at-home care (Davis et al., 2014; Lawson et al., 2017). Psychological input, social support (formal or informal), self-care opportunities, and respite are suggested to improve caregiver wellbeing and manage this grieving process (Mastel-Smith & Stanley-Hermanns, 2012; Toms et al., 2015). Our findings strongly support these recommendations.

### Clinical Practice Implications

**Education and communication of risk.** DBS is a complex intervention involving substantial preoperative medical

information for patients and families to digest. Desperation to undergo surgery, disease-related cognitive issues, and surgery-related anxiety can all affect patients' comprehension and recall of information. No clinical guidelines specifically outline the informed consent process for DBS in PD, and there is high variability in how preoperative procedures are conducted across individual clinicians, hospitals, and geographic locations. There has been very little research on patient comprehension of complex DBS risk information and ways to facilitate this. The current study highlights particular areas in the communication of DBS-related risks and outcomes that require consideration, while keeping these inherent challenges in mind.

The language and labels clinicians use to describe changes to patients and families will vary according to personal preference and how they conceptualize them. A drawback for using *personality change* is its confronting nature and potential to discourage prospective patients. In our preoperative interviews, however, only some were concerned about potential personality change and none sufficiently so to dissuade them from their decision. A benefit of using *personality change* is that it holds meaning for patients and families and manages to encompass a variety of potential changes in patient mood, behavior, and cognition. Clinicians may need to explore this meaning with patients and caregivers, including what they value most about the patient's personality. This would provide an opportunity to clarify and reassure patients and caregivers of what is unlikely (e.g., become a monster) and what is possible (e.g., irritable, impulsive, impatient).

The transience of stimulation-related personality changes is a particularly important aspect to reiterate with patients and families. In a comprehensive review of neuropsychiatric symptoms associated with DBS for PD, Voon et al. (2006) proclaim the majority are "transient, treatable and potentially preventable" (p. S305). Emphasizing the *transient* nature of personality change will likely reduce patient and family apprehension and initiate an understanding that treating them depends on communication and feedback between the clinician and themselves. This does not preclude DBS from potential long-term effects. Even after amelioration through stimulation reprogramming, a patient's uncharacteristic and problematic behavior can have lasting repercussions for the caregiver and spousal relationship (Mosley et al., 2019). Our results reflect how disappointment with the procedure outcome and stimulation-related side-effects (e.g., speech, balance issues) can have an indirect lasting effect, particularly on mood and self-confidence. These findings support the need for providing nuanced and contextualized information to patients (Bell et al., 2010).

Participants' awareness of ICDs and compulsive behaviors as a DBS side-effect was limited. It is possible

this information was provided by the clinical team, but not retained and recalled by our participants. It is also possible it was not discussed due to time constraints, the need to prioritize surgical information, the assumption another team member addressed it, or a clinical decision that it was not relevant to the patient. Educating patients and families on this matter is made difficult by conflicting clinical trial results. DBS has been reported as worsening existing ICDs and producing de novo cases, while also being reported as improving existing ICDs and producing only few, transient de novo cases (Averbeck et al., 2014; Eisinger et al., 2019; Kim et al., 2018). The relationship is particularly complex with multiple factors involved, including lead placement, implantation site, levodopa dosage, neuropsychiatric history, and stimulation programming. For patients with an existing history of ICDs, nuanced clinical discussions are required to explain these potential outcomes (e.g., reduced levodopa may improve ICDs, but DBS could exacerbate), intentions for managing it (e.g., taking a cautious stimulation approach), and the implications for procedure outcome (e.g., possible reduced clinical benefit). In the current sample, some patients and caregivers required greater clinical reassurance around these particular issues. Conversely, those without existing ICDs or psychiatric history were confident they would go unchanged by DBS. Although statistically at a reduced risk, cases of de novo ICDs and behavioral changes have been reported in patients with no history, so should not be discounted as a potential outcome (Mosley et al., 2019; Voon et al., 2006).

Participants' limited awareness of post-DBS personality change and expressed desire for more preoperative information suggests clinical communication on this topic requires improvement. Direct education from clinicians to patients and caregivers does not guarantee information is retained or ensure preparedness to manage changes (Mosley et al., 2019). More experiential information that uses the words and language of other PD patients and families has been suggested for improving comprehension and setting realistic expectations (Liddle et al., 2019). Our interviews demonstrated personal experiences from other DBS patients and families were well retained by participants and influential in establishing their expectations. Exposing prospective patients and families to a selection of patient experiences and outcomes could assist comprehension and increase preparedness to manage post-DBS difficulties (not just personality change, but balance and falls, speech and communication). Vignettes with patient experiences could be shared via multimedia presentation. An existing psychoeducation program developed to target psychosocial maladjustment after DBS has incorporated multimedia into their education, using videos to demonstrate potential outcomes (e.g., patient displaying apathy; Flores Alves Dos

Santos et al., 2017). Encouraging long-term results for patients in this program has been reported, albeit from a small sample, particularly across social adjustment and psychological health domains. Other program features that benefit comprehension are the spread of information across seven sessions, some prior to DBS and some following. Each session has a particular focus: neurosurgery, social, or couple-related content, with appropriate disciplinary input as required (neurosurgery, neurology, psychology, psychiatry). The separation of surgery- and psychosocial-focused information likely aids comprehension of each, and delivering at a relevant time increases its practicality. Programs of this type ensure timely education is provided (e.g., information on lesion effect, postoperative confusion prior to surgery); that concerns can be raised and addressed (e.g., process for ceasing medication prior to surgery); and opportunities exist for clinicians to assess comprehension, correct inaccurate beliefs (e.g., DBS causing problem drinking), and address unrealistic expectations. This program was designed for both patients and caregivers. Involving caregivers in the informed consent and education process is essential (Haahr et al., 2013), with preparedness shown to temper caregiver strain and assist coping (Carter et al., 2010; Mastel-Smith & Stanley-Hermanns, 2012).

*Follow-up clinical care.* In addition to DBS education and preparation, postoperative support and clinical care also requires consideration. The psychoeducation program evaluated by Flores Alves Dos Santos et al. (2017) included postoperative sessions to assist the transition from DBS preparation to management and adjustment. This provided patients and caregivers with practical psychosocial support in the months immediately following surgery. The format of DBS postoperative care in clinical settings more broadly is incredibly variable. Ongoing neurology consultations are standard treatment, but follow-up neuropsychiatric assessments are not always routine, despite being recommended for detection and management of mood and behavioral changes (Voon et al., 2006). Neurologists, who typically are familiar with their patients and existing personalities, often detect changes or enquire about them, but face the challenge of time constraint (Thomson et al., 2019). Access to a multidisciplinary team (e.g., PD nurse, general practitioner, social worker, psychologist, or psychiatrist) gives patients and families increased opportunities and time to discuss psychosocial issues and receive relevant support. Nurse specialists in particular are recommended as they can assist with device practicalities while assisting emotional adjustment (Haahr et al., 2020). They can also provide continuity of care across the patient's wider illness and treatment trajectory (Eatough & Shaw, 2017; Vann-Ward et al., 2017). In the case of ICDs, some may prefer

disclosing to a nurse rather than a specialist doctor (Thomson et al., 2019). However, disclosing can also be affected by poor insight, shame, embarrassment, or seeing them as a trade-off for other improvements. Patients and caregivers may feel more comfortable disclosing on a validated questionnaire, such as the Questionnaire for Impulsive-Compulsive Disorders in Parkinson's Disease (Weintraub et al., 2009) or Frontal Systems Behavior Scale (Stout et al., 2003). These can serve as screening tools to prompt sensitive conversations. These questionnaires need to be considered in the context of the patient's premorbid personality with verbal feedback from patient and caregiver. Hypervigilance to *de novo* changes could result in typical behavior being pathologized. If a mild personality change comes with improvements in other symptoms, a discussion between patient, caregiver, and clinician needs to occur to establish the acceptability of this trade-off.

### **Strengths and Limitations**

The design of the present study possessed important strengths. The patient-caregiver dyads allowed multiple perspectives on the patient experience and insight into the broader impact on the caregiver and their relationship. The prospective approach ensured participants' expectations, knowledge, and concerns accurately reflected current circumstances, which were then contrasted with actual outcomes and experiences. Semi-structured interviews and open-ended questions allowed for ambiguity, contradiction, and complexity in responses, reflecting the true nature of human narratives and meaning-making. This avoids issues of restriction associated with binary (yes/no) or predetermined response methods (de Haan et al., 2017; Hariz et al., 2016).

These results reflect the experiences of a subset of patients and families from a particular region and may not generalize to patients and families elsewhere. However, great diversity in DBS clinical practice exists, regardless of physical location, leaving generalizability of results an ongoing research issue. Although our interest rested in the common experience of undergoing DBS, purposive sampling ensured diverse experiences were captured (e.g., in age, disease length, symptom profile, implantation site, treating clinicians). Regrettably, only patients undergoing DBS through the private health care system were included. Attempts were made to include patients in the public system, but lengthy and uncertain surgery waitlists affected opportunities for participation.

### **Conclusion**

Post-DBS changes in personality were experienced by participants in this study. The stimulation was considered

to be only one of the many causes for the observed changes, and in each of these cases, the effects were either transient or minor. Personality changes directly affected caregivers and were most pronounced when they were associated with disease progression. The negative influence of illness on patients' personality and sense of self was apparent. For some, DBS facilitated a restoration of the patient's premorbid self. Perceptions of control were also relevant to patients, and future research should consider approaches for optimizing this across both standard PD and DBS care.

Patient and caregiver awareness of personality change as a post-DBS risk appeared limited, suggesting education and communication around these issues could be improved. Further studies are required to evaluate the benefit of perioperative psychoeducation programs for this purpose. With exceptions in obsessive-compulsive disorder (de Haan et al., 2017), how DBS affects personality and selfhood in psychiatric conditions has rarely been explored. As psychiatric indications for DBS emerge and develop, so should our understanding of the intervention's broader psychosocial impact.

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### **Supplemental Material**

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