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Staying "True to You" with Deep Brain Stimulation: A Values-Based, Caregiver-Informed Approach to Personality and Identity Changes Post-Implantation

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by Meghan Hurley
B.S. Emory University, 2021

Advisor: Jonathan K. Crane, PhD

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Abstract

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Deep brain stimulation has emerged over the last few decades as a promising treatment for a variety of neurological and neuropsychological disorders. Despite its efficacy in symptom reduction, some patients have reported negative or unwanted changes to aspects of their personality and identity that have posed challenges to their relationships and quality of life post-DBS. Moreover, these reports have sparked a contentious ethical debate about whether these changes pose a threat or harm to patient personality and identity and what an appropriate response to them may look like. As accounts from patients themselves regarding the nature of such changes continue to grow, caregivers remain an overlooked and understudied stakeholder in conversations about personality and identity change post-DBS. As such, the primary aim of this thesis is to explore the impact of DBS on patient personality and identity through the eyes of caregivers by identifying relevant themes and their frequencies in caregiver responses. With these insights, I introduce a values-based exercise for patient-caregiver dyads to articulate their own perceptions and conceptualizations of patient identity and personality pre-DBS. I propose that this exercise can help patients make more informed decisions about their care in the event that their caregiver perceives identity and personality changes post-DBS.

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Table of Contents

Introduction 7

Goals and Objectives Stated 8

- Research Questions 9
- Organization 9

Chapter 1: Background 10

- Brief History of Neuromodulation 10
- Deep Brain Stimulation 11
  - Ethical Concerns 12
    - Changes to Identity 20
    - Changes to Self (and Authenticity) 21
    - Changes to Personality 23
    - How Can We Know that DBS Poses a Threat to Patient Identity and Personality? 25
    - The Importance of Relationality and Relational Identity 26
    - Role of Caregivers 29

Chapter 2: Methodology 30

- Research Design 30
- Study Organization and Data Collection 32
- Data Analysis 34

Chapter 3: Results 35

- 3.1 Personality 35
  - Pre-surgery Interviews 35
  - Post-surgery Interviews
  - Table 2. Negative personality / behavioral changes 38
  - Table 3. Persistent patient characteristics post-DBS surgery. 39
- 3.2 Identity-related Concepts 40
  - Pre-surgery Interviews 40
  - Table 4. Notable quotes regarding patient identity and their disorders pre-aDBS surgery. 41
  - Post-surgery Interviews 41
  - Table 5. Caregiver perspectives of observed identity persistence post-surgery. 42
  - Table 6. Further comments relating to the impact of DBS on identity. 43
- 3.3 Dimensionality of Identity and Personality Persistence 43
- 3.4 Changes Perceived by Others 45
  - Table 7. Personality and identity changes perceived by others. 46

Chapter 4: Discussion 46

- Personality Changes 47
- Identity-Related Changes 51
- Dimensionality of Identity and Personality Changes 53
- Relational Identity and the Value of External Perspectives 56
- A Way Forward? Caregiver Perspectives in DBS Decision-Making 58
- In Practice 64
- Limitations 67
- Conclusion 68

References 70

Appendix A: Staying “True to You” with DBS Patient-Facing 88

Appendix B: Staying “True to You” with DBS Caregiver-Facing 91

Introduction

Over the past several decades, deep brain stimulation (DBS) has emerged as a treatment for a variety of refractory, or treatment-resistant, neurological disorders. Utilizing electrical stimulation to modulate brain activity in a variety of specific brain regions, DBS is currently approved as a therapy for movement disorders such as Parkinson's disease (PD), dystonia, essential tremor (ET), and epilepsy. Most recently, it has begun approval for neuropsychiatric disorders such as obsessive compulsive disorder (OCD) and continues to be researched as a treatment for a range of other conditions such as Tourette syndrome (TS), schizophrenia, Alzheimer's, eating disorders, and more (Sullivan, Olsen, and Widge, 2021). Thus far, randomized controlled trials have emerged to investigate the efficacy of DBS for OCD and major depressive disorder at various targeted brain regions (Wu et al., 2021 and Figee et al., 2022 respectively) and, while DBS has yet to become an FDA-approved intervention for all of these psychiatric disorders, research studies continue to examine the utilization of DBS for these conditions.

In addition to clinical studies, ethical analyses of deep brain stimulation for both movement disorders as well as psychiatric disorders have identified concerns regarding the impact of DBS on identity and personality (Baker, 2023; Schermer, 2011; Schechtman, 2010). While these concerns exist with movement disorders—especially with conditions such as PD, which has physical symptoms often accompanied by psychological ones, such as mood changes, and even depression—they are made more complex and potentially exacerbated by the nature of psychiatric disorders considering the overarching goal of psychiatric treatment—to elicit changes in patients' condition-driven behaviors and emotional states. Considering the impacts that psychiatric disorders themselves already have on how patients act, feel, and perceive, and thus, affect one's sense of self and self-concept, discussions of how DBS may alter patient identity and personality are particularly relevant for psychiatric populations (Snoek et al., 2021). Attempting to distinguish these desirable changes from unwanted or negative changes is a specific challenge for DBS's use in treating psychiatric disorders (though in movement disorders as well). This challenge has led scholars to ask what is a personality, whether personalities can be fundamentally changed or altered, what are the ethics of changing someone's personality, and what it means for identity that personalities are pliable, and patients to question how their identity and personality transform from pre-diagnosis to living with the condition to post-treatment, as well as how such changes impact their agency, subsequent behaviors, interpersonal relationships, and decision-making.

Goals and Objectives Stated

This thesis analyzes caregiver perceptions of identity and personality changes in patients as a result of DBS and offers a novel method for integrating caregiver perceptions into post-implantation decision-making that is grounded in the concept of relational autonomy. Although studies involving the perspectives of caregivers have become more common in the deep brain stimulation literature (Brezovar et al., 2022; Chacon Gamez, Brugger, & Biller-Andorno, 2021; Thomson et al., 2021; Mosley et al., 2021; Lewis et al., 2015;), there is still a limited amount of empirical evidence displaying the perspectives of both caregivers and patients. Few publications seek to explore the insights that caregivers may provide about perceiving, measuring, or labeling identity and personality change in others as well as the implications of this data on the role that caregivers may play in validating, bolstering, or further informing patient narratives and experiences of these changes and their impact on quality of life.

Research Questions

This thesis aims to fill several knowledge gaps in the literature by investigating the following questions:

1. **How do caregivers perceive personality and identity changes in patients who have undergone DBS[1] for various conditions?**
2. What language do caregivers use when discussing or describing patient personality and identity?
3. What kinds of traits, characteristics, or actions do caregivers attribute to personality versus identity?
4. How should caregivers' perceptions of patient personality and identity changes be integrated into the ethical practice of DBS?

As will be explained later, this thesis draws upon data from a recent research study of caregiver perceptions of identity and personality in post-DBS patients. I will unpack how the study data directly speak to questions one through three. I will also offer my interpretation and original insights regarding question four. Specifically, I propose a novel tool that can be utilized by the patient-caregiver dyad to enhance the quality of post-implantation decision-making in the event that a caregiver perceives personality or identity changes in their loved one.

Organization

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[1] The patients who participated in this particular study were implanted with an adaptive deep brain stimulation (aDBS) device, a next generation version of DBS devices that records and incorporates neural activity data while automatically adjusting stimulation. While these types of devices raise novel ethical considerations worthy of acknowledgement (see Adaptive Deep Brain Stimulation for more on this), stakeholders were asked more generally about the impacts of the patient's "DBS" on concepts like personality, identity, and authenticity. Study questions did not touch on comparisons between DBS and aDBS or ask stakeholders in particular about the experience of aDBS. Because of this, the term DBS is used throughout this thesis to refer to patients' neurostimulation devices and my analysis is more broadly aimed at DBS.

Structurally, this thesis is split into four chapters. Chapter One consists of a brief history of neuromodulation and deep brain stimulation and a thorough literature review of current ethical concerns relating broadly to DBS, and more specifically, to personality and identity changes and the subjective issue of quality of life with DBS. This chapter aims to situate the reader within the vast DBS literature and is necessary for understanding the significance and novelty of the research questions and overall study. Chapter Two outlines the methodology and research design utilized for the study upon which this thesis draws. The results, in the form of notable quotes and commonly occurring themes, are presented in Chapter Three. The discussion section, Chapter Four, will examine the relevant themes that emerged from the data, situating them in the existing identity and personality change literature, and will propose and explore the novel use of a values-identification tool for assisting patients and caregivers in identifying and maintaining patient and caregiver desires regarding personality and identity post-implantation. The thesis will conclude with an acknowledgement of study limitations and suggestions for further investigations of this topic.

Chapter 1: Background

Brief History of Neuromodulation

The history of deep brain stimulation (DBS) can be traced back to early versions of neuromodulation and psychosurgery. As early as the 1890s, physicians were beginning to explore the benefits of utilizing electricity to anatomically map and potentially alter the brain (Pyle, 1893). In the 1930s, this practice gained more attention with clinicians and researchers such as Wilder Penfield who began to use electrodes to stimulate different areas of the brain in an effort to explore their function (Gardner, 2013). Though common treatments at the time for mental and neurological disorders consisted of ablation and lobotomy, lobotomies were based on little clinical evidence, lacked sterile technique, resulted in fairly global brain damage, and often produced poor patient outcomes and debilitating complications, such as apathy, aggression, and social disinhibition (Caruso and Sheehan, 2017; Faria, 2013). Around the 50s and 60s, a rise in pharmacological interventions to treat psychiatric conditions combined with public acknowledgement of the ethical atrocities associated with lobotomy largely caused the use of psychosurgery for mental illness to fall out of favor. Nevertheless, other researchers saw the potential for psychosurgery to become a successful therapy; with the introduction of stereotactic surgery and imaging technologies to more safely and precisely locate brain target areas, as well as a pacemaker-like electrode for neurostimulation, came the creation of deep brain stimulation.

Deep Brain Stimulation

By this time, clinics and centers across the United States and throughout Europe conducted DBS studies that utilized electrodes implanted deep into the brain and that successfully achieved symptom alleviation in a variety of neurological and neuropsychiatric conditions (Ellis, 2011, Heath et al., 1980; Heath, 1977; Hosobuchi et al., 1973). In the United States in particular, Robert Heath's experiments focused more on psychiatric disorders such as schizophrenia, becoming an early physician to implant deep cortical electrodes in psychosurgery. Despite Heath's significant work in the field, he was an extremely controversial figure in the history of DBS, with many articles about his life's work emphasizing his unethical surgical practices and his utilization of stimulation to "cure" homosexuality (O'Neal et al., 2017). Irresponsible neurosurgeons and physicians like Heath, Walter Freeman, and Egas Moniz have all contributed to the ethically fraught origins of DBS, which—despite fueling some negative perceptions of the approach (Cortright et al., 2023; Outram et al., 2021)—has not prevented modern-day patient willingness to pursue DBS. By the 2000s, DBS had become a fairly common treatment for Parkinson’s disease (PD) (Gardner, 2013), and soon after, researchers began to explore DBS for other movement disorders like essential tremor (ET) and dystonia (Ashkan et al., 2013; Pycroft, Stein and Aziz, 2018), as well as for intractable psychiatric disorders (Vedam-Mai et al., 2021; Ashkan et al., 2013). Studies published on the use of DBS for Tourette syndrome, treatment-resistant depression (Bergfeld et al., 2016; Jimenez et al., 2013; Lozano et al., 2008; Mayberg et al., 2005), obsessive compulsive disorder (OCD) (Alonso et al., 2015; Mallet et al., 2008) ushered in a new era of DBS for psychiatry that persists today.

Modern versions of DBS consist of the implantation of an electrode that delivers steady, continuous pulses of electricity into specified deep regions of the brain, in order to modulate neural function and alleviate symptoms associated with neurological and psychiatric conditions (Pycroft, Stein, and Aziz, 2018; Kringelbach and Aziz, 2009). Targeted areas of the brain typically include brain regions that mediate mental states involving emotion and cognition, as well as motor control. In many cases, the electrodes are connected via cables to a battery-driven pulse-generator that is located in the patient’s chest, and can be controlled remotely (Glannon, 2009). Even with FDA approval for the use of DBS as a therapy for certain conditions, DBS clinical trials persist throughout the United States to solidify empirical evidence of its benefits, to test its effectiveness for a variety of other conditions, and to assess the most effective target brain regions for each condition.

Ethical Concerns

As with many emerging neurotechnologies, deep brain stimulation raises important ethical concerns that are only made more complex as its applications and types of devices expand. With the ethically questionable history of psychosurgery and DBS’s quick rise to prominence as a sought-after treatment for a variety of conditions, ethicists have made a point to emphasize the highly invasive nature of DBS, and the need to balance its risks and benefits—both physical and ethical—before offering it to patients or for determining patient candidacy (Schermer, 2011). For many, DBS is an invasive last resort to manage their severe and treatment-resistant conditions, which can lead to unrealistic hopes and expectations of the treatment (Bell et al., 2010). Treatment search fatigue, coined by Zuk and Lázaro-Muñoz in their 2020 publication, in combination with symptoms over time like cognitive decline that may impair patient decision-making capacity, lead to questions about informed consent, coercion, and autonomy for patients who are desperate to try a new therapy (Stevens and Gilbert, 2021; Zuk and Lázaro-Muñoz, 2021; Glannon, 2009).[2]

In recent years, adaptive deep brain stimulation (aDBS), a type of closed-loop next generation DBS device, has also emerged as a prominent new therapy. Closed-loop systems utilize a sensor that records brain activity in addition to modifying it, so that the electrode, in combination with what are often machine learning approaches that identify patterns in neural activity, can readjust the amount of electricity delivered to the patient in real-time based on the detection and prediction of symptomatic events (Parastarfeizabadi and Kouzani, 2017). Despite benefits like reduced side effects and more precise stimulation (Frey et al., 2022), novel ethical concerns[3] with aDBS and patient autonomy, agency, and control are worthy of acknowledgement here.

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[2] Other pressing ethical concerns highlighted in the DBS literature include justice / access disparities (Memon et al., 2023; Sarica et al., 2023; Goldberg, 2012, pediatric applications and their impact on child development and open futures (Kostick-Quenet et al., 2023; Muñoz et al., 2021; Scaratti et al., 2020; Schermer, 2011), continued access / explanation (Sierra-Mercado, 2019), and the impact of DBS on interpersonal relationships (Thomson et al., 2023; Saleh and Hasler, 2017), which I will return to later in this chapter.

[3] Another important ethical concern, though of less relevance to this thesis regards data security and privacy and the combination of neural activity recording with delivery of electrical stimulation that we see in aDBS devices (Baker et al., 2023). Whether or not recorded neural activity is deemed as protected health information similar to other health data, how this determination impacts neural data storage and sharing practices, and how ownership and privacy challenges should impact informed consent for data collection and aDBS implantation are all important ethical considerations to discuss as data-driven practices continue to improve precision in neurointerventions.

In particular, the automaticity of reprogramming in aDBS devices raises concerns about patients' lack of conscious awareness of stimulation changes, relinquishing a patient's ability to exercise autonomy over their actions and behaviors, potentially steering them towards a personality that the patient themself does not recognize or identify with (Klein et al., 2016; Gilbert, 2015a). DBS researchers in particular have emphasized the important ethical implications of this ability, considering aDBS devices are able to make real-time decisions about whether to administer therapy and adjust a patient's mental state, without input or clearance from a physician. In a study that explored researcher perspectives of pressing ethical issues related to aDBS, over half of respondents noted concerns about patient autonomy and control over their stimulation and mental states (Muñoz et al., 2020), as aDBS devices that automatically adjust their parameters may make patients wonder whether the device is "controlling" their brain, rather than their brain states controlling their device settings (Goering et al., 2017). Similarly, Baker et al. (2023) notes concerns about aDBS's automaticity undermining a patient's ability to produce authentic[4] behaviors and affective states or to act in accordance with their "true self."[5]

An ethical concern particularly pertinent to the goals of this paper and intertwined with these issues of autonomy, authenticity, and agency, deals with the issue of patient's subjective perception of benefit from DBS and questions of quality of life (Kubu and Ford, 2017). I have already noted the importance of weighing both the benefits and potential risks of DBS when considering it as a treatment, especially given that patients may view this intervention as a last

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[4] The concept of authenticity is a vast and well-discussed topic, philosophically. In the context of aDBS, I use the term "authentic" behavior to refer to behaviors that appear to be in line with or true to established behaviors in the patient that they identify with. The philosophical concept of authenticity will be discussed in more depth in relation to the self and perceived selfhood in the section Changes to Self (and Authenticity).

[5] To offset some of these concerns, scholars emphasize the importance of educating patients about exactly what aDBS devices can and cannot do, to dissuade currently hype-driven concerns about "mind reading" or "mind control" that may arise for patients afraid of their neural signals being manipulated by neurostimulation devices.

resort option to alleviate the symptoms or condition that impairs their ability to interact socially, perform certain tasks or hobbies, and overall, to reach the quality of life they desire. Because improving quality of life is so often the goal with DBS users, improving functionality and subjective metrics that the patients themselves deem essential for enhanced quality of life is crucial for attaining patient satisfaction with the benefits of DBS. In other words, while DBS may be effective in alleviating certain marked symptoms of the condition in question, actual patient benefit depends on the patient's perception of whether or not such symptom mitigation has allowed for an improved quality of life. As Synofzik and Schlaepfer describe it in their 2008 paper, "pure effectiveness of the [DBS] intervention with regard to the neurological and motor functions is normatively meaningless. The ethical justification [of pursuing DBS] depends on the benefit for the patient; for this, the effectiveness is an important prerequisite but not a sufficient one."

Given the extremely subjective and value-laden nature of quality of life, however, patient benefit may look different for everyone, and while one individual feels as though their tremor reduction has facilitated a better quality of life than they previously experienced, another patient with the same tremor severity and same, objectively measured symptom improvement may still not be able to go on outings with loved ones without self-consciousness and or difficulty; it is the normative difference between the two that really matters, and that determines patient satisfaction or benefit. Glannon (2009) similarly emphasizes quality of life as a key factor in this analysis, noting that a patient's decision to pursue DBS hinges on deciding whether the "emotional suffering from loss of motor control is worse than changes in other states of mind." Patients may also be dissatisfied with other spheres of life post-DBS implantation that prevent them from benefitting despite effective treatment of symptoms—social support, emotional well-being, interpersonal relationships, and ability to perform hobbies can all suffer, for example (Ferrara et al., 2010; Drapier et al., 2005) and patients may struggle generally with “socio-familial maladjustment,” in which they struggle to return to previously held familial or social roles and responsibilities (Agid et al., 2006). This issue of patient subjectivity and quality of life with DBS also spills into important ongoing debates about DBS-induced threats to patient personality and identity, and authenticity.

Thus far, this ethical concern has been most extensively discussed in the theoretical literature and treated more as a potential problem than a real one due to insufficient empirical evidence of the frequency and magnitude of identity and personality changes in DBS patients (Gilbert et al., 2021), though empirical evidence has been mounting in more recent years (Merner et al., 2023; Wilt et al., 2021; Gilbert et al., 2017; de Haan et al., 2017; de Haan et al., 2015; Castelli et al., 2006). Regardless, an overview of the empirical data collected on changes to patient personality, identity, and mood and behavior broadly, shows that reports have been largely mixed. While a handful of studies have reported no significant changes to personality, identity and related concepts, or merely transient ones, such as initial anxiety post-surgery that alleviates once a patient’s stimulation parameters have been solidified, or mood changes that were reported by patients but unlikely or not clearly linked to DBS implantation (Pham et al., 2015; Boel et al., 2015; Appleby et al., 2007; Houeto et al., 2006; Temel et al., 2006), patients in other studies have reported both positive and negative changes to personality and identity. Positive changes for patients dealing with both neurological and neuropsychiatric conditions like PD, OCD, and treatment-resistant depression have included a general reduction of anxiety, depression and neuroticism, a feeling of returning to desired or valued personality traits, feelings of aligning more with their genuine or pre-condition selves, and overall movement towards hope and more positive emotionality (Thomson et al., 2020; Ramasubu et al., 2021; de Haan et al., 2017; de Haan et al., 2015). Some patients have even noted feeling like “a new and improved version” of themselves or that they’ve had a “second birth” (Nyholm and O’Neill, 2016).

Others have reported more unwanted effects from DBS. Patients from several studies have noted general apathy, lack of motivation, narrative disruption (i.e. a disruption in the narrative that a patient has constructed of their life and identity from past memories, experiences, etc.), feeling far off from their ideal self, and difficulty readjusting to their normal, social lives despite surgical success and general alleviation of symptoms (Thomson et al., 2023; Gilbert, 2012; Gisquet, 2008; Agid et al., 2006). One qualitative study interviewing patients about their post-DBS experiences, for example, noted that patients who experienced self-alienation from their illness also appeared to experience post-operative self-estrangement (described as an involuntary shift in character), sometimes in a deteriorative manner (Gilbert et al., 2017). Several early DBS studies for patients with PD also reported concerning issues such as suicidal ideation, suicide and hypomania (Witt et al., 2008; Soulas et al., 2008; Voon et al., 2008; Schuepach et al., 2006). Other studies with PD patients specifically reported impulse control issues such as pathological gambling, general increased risk-taking, and hypersexuality (Frank et al., 2007; Schuepbach et al., 2006; Herzog et al., 2003). Moreover, studies have noted psychiatric complications in movement disorder patients in general, including depression, apathy, transient aggression, hypomania, mania, anxiety, and emotional hyperreactivity (Houeto et al., 2002; Ashkan et al., 2013).

In some cases, patients who experience these complications, for example hypomania, have been unaware of their changed mental state, and thus decline any offers to readjust their DBS device settings (Schermer, 2011). In addition to these more direct, psychologically altering complications, some studies have recorded cognitive impairments such as issues with memory or focus as a problem after DBS surgery for some patients (Foki et al., 2018; Massano and Garrett, 2012). Unsurprisingly, these unwanted, negative changes to personality and identity have also been reported to impact patient relationships and connection, with patient-caregiver and patient-partner dyads experiencing increased conflict from changes (or lack thereof) in relationship dynamics, responsibilities, and patient motivation (Thomson et al., 2023).

In spite of this growing literature, a large challenge of collecting empirical evidence "proving" that DBS causes changes to patient personality and identity is the difficulty of showing direct causation, that such changes are occurring because of DBS specifically rather than alongside stimulation or as a secondary effect of symptom reduction/alleviation or surgery (which is sometimes reduced to "adjustment difficulties") (Merner et al., 2023; Snoek et al., 2021; Gilbert et al., 2021; Pugh, et al., 2021).[6] For some, establishing this causal relationship is crucial for deeming DBS a "threat" to patient personality and identity; should these changes be side effects of aspects of DBS or merely a part of the chain of events that subsequently occur from DBS, they may be viewed as more acceptable, justifiable, or merely an inevitable feature of DBS that needs to be adjusted to after implantation. Despite not knowing for certain that changes have been directly produced by stimulation, and even if they are not monocausal, efforts to expand the breadth of empirical data detailing these changes from various stakeholder groups continues as we attempt to better understand the normative importance of the challenges faced by patients post-DBS (Snoek et al., 2021).

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[6] Aside from surgery, they could also be related to inevitable disease progression, especially for neuropsychiatric conditions (Gilbert et al., 2021), or biological structures, given that targeted brain regions, neuroanatomy, and condition manifestation vary so significantly by study and individual (Hoy, Little, and Chiong, 2023). Establishing this connection becomes even more difficult without the use of randomized controlled trials that allow for comparison between experimental and control groups.

Parallel to the growth of the empirical literature for this ethical concern has been the growth of a robust theoretical literature exploring and examining the normative value of DBS-induced personality, identity, and related changes to patients and trying to understand the impact of DBS on patients' sense of self. The idea that our personalities and selves have the potential to be altered by invasive, foreign objects has persisted since the time of lobotomies, electroconvulsive therapy, and the well-known story of Phineas Gage, whose brain was impaled by a rod in the 1800s and whose personality arguably changed for the worst alongside it (Ford, 2006). As such, the idea that deep brain stimulation may be able to alter personality and related concepts given its modulation of brain states is well established in the theoretical neuroethics literature and has been explored by a wide range of ethicists and philosophers. After a seminal 2006 publication from Schuepbach et al. detailing impacts to patient self-perception after patients with Parkinson's disease received electrical stimulation, the literature saw a substantial increase in theoretical neuroethics publications. Early notices of these claims in the literature appear to occur in the mid-2000s by Gisquet, who refers to DBS as a "disruptive experience which redefines the patient's life," and describes its "destabilizing" effect on the continuity of patients' identity narrative (Gisquet, 2008). Other interpretations quickly followed, from Schechtman (2010)'s influential categorization of DBS as a "threat to personal identity and agency," to Witt et al. (2013)'s similarly negatively connotated language, that patients are at "risk of becoming another person following [DBS] surgery"[7] and that this risk is "alarming." For

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[7] An interesting ethical consideration arises related to informed consent should a patient "become a different person" following DBS surgery. One very influential case, referenced often in the literature, features a Parkinson's patient who was hospitalized for mania and became subsequently deemed mentally incompetent following DBS implantation. Although adjustment of the patient's stimulation parameters restored cognitive capacity, it also resulted in the return of debilitating motor symptoms, causing the patient to become bedridden. With DBS turned off and the patient deemed competent to consent, the patient ultimately made their decision to live legally committed to a chronic ward in a psychiatric hospital with mania. Ethical debates about this case center around whether the patient has forfeited their autonomy and capacity to consent to future continuation or discontinuation of DBS and how the medical team should proceed given that the patient's choice would change his state of mind (Glannon, 2009).

the purpose of this thesis, I will briefly explore philosophical definitions and understandings of these concepts to demonstrate their complexity and the challenges faced by stakeholders attempting to understand how and if they change and fluctuate in post-DBS patients.

Changes to Identity

To better illuminate the sort of threat that DBS may pose to patient identity, philosophers and neuroethicists have developed theories of personal identity to explore the ethical implications of such potential harms. One concept, narrative identity[8], is a frequently adopted framework for understanding personal identity and a central concern to discussions of the impact of DBS on identity (Leuenberger, 2021; Pugh, 2020; Goddard, 2017; Mueller, Bittlinger, and Walter, 2017; Baylis, 2013; Lipsman and Glannon, 2013; Schechtman, 2010; Glannon, 2009). Narrative accounts of identity often grapple with the question of what beliefs, desires, and values make a person who they are (Schechtman, 1996) and assert that people construct their own narratives made up of memories and experiences to make sense of and interpret their own lives (Lipsman and Glannon, 2013). These narratives, together with personality and behavior, result in a dynamic, constantly evolving identity that incorporates changes to ensure that the narrative remains cohesive as people go about their lives (Pugh, 2020). Constructed narratives may also be informed by personal relationships and experiences, extending narratives outside just the personal sphere. Because of this, alterations to the personal narrative of patients via substantial behavioral changes could drastically transform family dynamics, relationships with significant

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[8] In addition to narrative identity, the philosophical literature also frequently acknowledges numerical identity, the sense of identity that deals with what it means to exist through time as the same individual. Given that a patient would need to experience significant changes to their psychology to create such a disruption of continuity, it is often argued that DBS is unlikely to impact patient numerical identity (Pugh, 2020; Lipsman and Glannon, 2013; Witt et al., 2013). Because of this, we focus primarily on the threat to narrative identity.

others and friends, and overall derail the life path and continuity that an individual has spent years curating and developing (Baylis, 2013).

Other scholars have utilized the term “individual identity” to refer to that same philosophical question of “who am I?” that arises when we examine the characterization of personal identity and that is linked to our beliefs, values, and what “makes you, you” (Witt et al., 2013). They posit instead that individual identity is built upon an individual’s core attitudes and propose the foundational-function model to argue that core attitudes for an individual lay the foundation for other, more peripheral attitudes and beliefs. Should these foundational attitudes “crumble” or change for any reason, Witt et al. argue, other beliefs would follow, causing what they refer to as a “paradigm shift,” a change big enough to reflect discontinuity between the pre- and post-self, the kind of change that would be noticeable to post-DBS patients (Witt et al., 2013).

Despite their prevalence in the literature, there are still challenges to utilizing these conceptions for DBS-induced identity changes and some disagreement as to which circumstances with DBS result in such significant changes to a patient that their identity is no longer the same as before the procedure. Discussion of what amount or extent of mental change would be substantial enough to alter one’s identity or narrative continuity persists, with most agreeing that subtle changes may not be sufficient, but others still divided about even the foundational belief that changes radical enough to cause a disruption in the continuity of one’s beliefs and attitudes worthy of concern are possible (Glannon, 2009). Alternatively, perhaps disruption need not be seen as a threat to identity at all (Baylis, 2013), or at least, not unless a patient herself finds the disruption to be problematic or a disruption to her normal, cohesive life narrative (Schermer, 2011). Baylis even suggests that patient consent to DBS may be seen as sufficient for endorsing or accepting identity changes into a new self-narrative in the first place.

Changes to Self (*and Authenticity*)

Similar to identity, the theoretical literature also examines theories of the concept of "self" or selfhood, to explore the changes experienced by patients post-DBS. These concepts are related, exploring alternative perspectives of the same central questions about what makes a person who they are, resulting in a decent amount of overlap with philosophical discussions of identity change (like the previously mentioned Witt et al., Schechtman, and Baylis). The self and selfhood literature focuses on the individual's own perspective of "who they are" and how genuine or "authentic" one's thoughts, feelings, behaviors, and actions may feel in comparison to "who" an individual feels that they are; Erler (2021) dubs this "subjective authenticity," Kraemer (2013), "feeling like one's self." An individual's idea of his or her true self may depend critically then on what he or she values at their core (Nyholm and O'Neill, 2016). Additionally, more peripheral values can potentially fluctuate without impacting the core aspects critical for authentic selfhood, and core values associated with the "true self" may even change and evolve as an individual lives their life and has new experiences. Whether or not a person is their true self may also be a matter of degree, with values and aspects that an individual deems best or most important closest to the core and representing more of the individual's authentic self, versus aspects that are further away or more superficial that may more easily change and fluctuate (Pugh, Maslen, and Savulescu, 2017; Nyholm and O'Neill, 2016).

In the context of DBS for example, de Haan et al. (2017) point out that some patients have felt somewhat alienated from new traits or behaviors post-DBS, but didn't seem to change their fundamental attitude about life and the world, suggesting that continuous change may need to be grounded by some fixed elements of the self, though others may be somewhat in flux. Others have described this phenomenon in terms of “self-estrangement” or “self-alienation,” describing patients who don’t recognize themselves, experience an altered body image, and don’t seem to share all of the same goals or preferences as their pre-DBS selves (Gilbert, 2018; Kraemer, 2013). Patients who see themselves more and more frequently exhibiting a particular trait that they don’t like, for example, may start to feel less like their “true self.” At the same time, DBS can also be seen to impact patient self and authenticity in positive ways, helping patients to actualize or realize their “true” self, or a better, more ideal version of themselves, especially when condition symptoms have shrouded authentic personal values (like in OCD) (Kraemer, 2013).

As with conceptions of identity, aspects of recognizing and measuring selfhood make it an equally complicated concept to use to explore the impacts of DBS on patients and their subjective experiences of such changes. It can be extremely difficult for patients to determine which perceived changes are authentic or in line with one’s current or established selfhood or identity and which aren’t—especially when a patient’s refractory condition has left them feeling some kind of estrangement for a significant period (de Haan, 2017). Nevertheless, scholars have proposed focusing on these patient’s subjective accounts of their authenticity to measure and potentially quantify such changes, like with self-ratings of estrangement (Erler, 2021) and standardized assessments for changes in self-perception (Eich, Mueller, and Schulze-Bonhage, 2019).

Changes to Personality

Beyond frameworks of identity and selfhood, the theoretical literature also explores theories of personality to better understand the kinds of changes being seen in post-DBS patients.

Scholars in the theoretical DBS literature often define personality as an organized set of characteristics influencing one's cognitions, motivations, and behaviors (Witt et al., 2013; Synofzik & Schlaepfer, 2008), though the value of using personality to understand DBS-induced changes may depend on asking the right questions—on which level and to what extent personality is affected, whether these changes are perceived as good or bad by the patient (Synofzik and Schlaepfer, 2008), what magnitude and kind of changes amount to a "meaningful" or "harmful" personality change, and who gets to determine the threshold for "problematic" (Snoek et al., 2021). Trait theories of personality, which focus on measuring specific personality traits and habitual patterns of behavior and thought considered to be relatively stable over time and across contexts (Eysenck, 1994), lend themselves well to operationalization for empirical measurement in DBS studies[9]. These personality assessment tools are often in the form of ratings and self-ratings given to patients or even caregivers in some cases[10], and though there is some variety, there are ultimately only a small number of existing scales with the goal of measuring personality-related changes (Gilbert et al., 2021).[11]

Although these measurement tools are frequently used in the DBS literature, they are not methodologically without flaws or challenges (Hoy, Little, and Chiong, 2023; de Haan et al., 2017; Mueller and Christian, 2011). Critics have raised concerns about the fit of clinical scales to

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[9] Examples of well-known trait models include the recent Big Five Model, which measures personality along five dimensions—Openness, Conscientiousness, Extraversion, Agreeableness, and Neuroticism (OCEAN), and older prominent models like Cattell's Sixteen Personality Factor Questionnaire and Allport's hierarchy of personality traits, consisting of cardinal, central, and secondary traits that carry varying weight in the individual's personality (Allport, 1931).

[10] One standardized assessment, the Iowa Scale of Personality Change, relies on the perspective of close family members who have regular contact with the patient, to assess personality across 26 clinical scales, like emotional expression, decision-making, and interpersonal relations (Iowa Scales of Personality Change).

[11] Most quantitative studies investigating personality change in DBS have used inventories like the Temperament and Character Inventory (TCI) and the Tridimensional Personality Questionnaire (Wilt et al., 2021; Pham et al. 2015) and the Neo-Five Factor Inventory, which reports on the same five traits as the Big Five, but also on six subcategories of each trait, dubbed "facets" Ramasubbu et al., 2021).

measure changes in personality traits (Hoy, Little, and Chiong, 2023) and the ability of quantitative, standard measurement scales to adequately capture or reflect changes to personality, mood, and behavior that are subjectively perceived by patients (Lewis et al., 2015), especially when patients do not get the chance to elaborate on the personal relevance of what is being measured and which characteristics they view as most salient.[12] Moreover, most studies utilizing these measurements to assess personality only ask patients, or caregivers when applicable, to assess pre-condition personality retrospectively, which—while not useless—cannot provide the most accurate or objective picture of how a patient's personality has changed over the course of DBS treatment Brezovar et al., 2022; Boel et al., 2016).[13]

Research continues in search of more reliable and objective instruments for assessing complex personality-related changes (Allen, Giordano, and Okun, 2023; Ineichen, Baumann-Vogel, and Christen, 2016; Witt et al., 2013) as well as accounts of personality that allow us to determine what makes a psychological trait change normatively significant (i.e., which changes matter and which don't). Regardless, some believe we need to reach agreement on more narrow definitions and understandings of these concepts first (Merkel et al., 2007), in order to have standardized language for better measurement (Zuk and Lázaro-Muñoz, 2021; Erler, 2021), better understanding of what we *should* be measuring (Snoek et al., 2021) and better discernment of their normative significance (Pugh, 2020). [14]

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[12] While qualitative measures can help to fill in some of these gaps about the patient experience, they have their own methodological weaknesses like limited generalizability (Wilt et al. 2021). At the same time, scales that rely solely on subjective self-reports of personality that lack external perspectives can lead to biases and/or an incomplete or inaccurate picture of patient changes.

[13] Pham et al. (2015) provided one of the first studies to utilize multiple measurements of personality with post-DBS patients and is one of few studies that measured personality both before and several months after implantation.

[14] It is important to acknowledge that concepts such as autonomy and agency, discussed briefly in the Ethical Concerns section, are often intertwined with these multifaceted concepts and frequently grouped into the acronym, "PIAAAS"—personality, identity, agency, autonomy, authenticity, self—(Pugh et al., 2021; Zuk and Lázaro-Muñoz, 2021; Erler, 2021; Gilbert et al., 2021) to more easily refer to and account for the breadth of potential normative changes to patients and their often overlapping or ambiguous boundaries. I have also touched only briefly

How Can We Know that DBS Poses a Threat to Patient Identity and Personality?

Despite continued disagreement as to whether or not DBS does indeed pose an imminent or serious normative threat to patients' identity and personality, it remains critical to gather as much new, empirical evidence as possible to gauge the severity, frequency, and valence of meaningful changes to patient personality, identity, self, and related concepts (Merner et al., 2023). Only by gathering empirical evidence and testimony from patients and those close to them can we continue to explore and attempt to qualitatively and quantitatively capture the phenomenological experience that post-DBS patients are going through. This evidence will be crucial in guiding future patient risk-benefit analyses of DBS, discerning the proper response to this ethical matter and for advancing philosophical theories of the concepts in question. In line with this goal, recent progress in the literature has focused on engaging other stakeholders for their perspectives on post-DBS changes to patients.

The Importance of Relationality and Relational Identity

An increasingly relevant form of identity that has been referenced in the DBS literature is relational identity (Baylis, 2013; Goering, 2014; Goering, Klein, Dougherty, and Widge, 2017; Martens and Brown, 2019; Goering, Brown, and Klein, 2021; Goddard, 2017; Mackenzie and Walker, 2015). In recent years, philosophers have emphasized that our self-narrative is not created in a vacuum—that our personal identity is shaped not only by interactions with others but also by the effect of others' opinions and perspectives of our identity on our self-conception and

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upon authenticity as it relates to changes of selfhood and identity, while a much bigger literature utilizing authenticity to frame identity issues in the context of DBS exists (Meynan and Widdershoven, 2014; Johansson et al., 2011). Although further examinations of such related concepts are relevant in these conversations, the complexity of each of these concepts individually, compounded by their unique relationships to each other, requires a much deeper and lengthier analysis than what can be presented here. The scope of this thesis and more specifically this chapter, will remain then on discussions of a subset of these concepts—identity, personality, and occasionally self—given that they are the primary focus of the study research questions and are significantly conceptually rich on their own.

overall self-knowledge (Boulicault and Brown, 2018; Vazire and Carlson, 2011). Laurence Thomas's own account captures this point nicely, in which he remarks that "the way in which we conceive of ourselves, at least in part, owes, much to how others conceive [of] us, and this is necessarily so. The way in which we think of ourselves is inextricably tied to the way in which others think of us" (Thomas 1998, 359-81), In our day to day lives, for example, our friends and loved ones witness the way that events and experiences affect us, both positively and negatively.

While we may perceive our own identity or personality change over time, this perception often contains omissions or gaps (Erler, 2021)—behavioral changes that may not seem value-concordant that we do not even notice, perhaps because we do not want to recognize the change, betray our values, or see ourselves in a negative or "true" light. Others may even be better at perceiving aspects of our identity or personality than we are, and this is especially true of undesirable traits (Vazire and Carlson, 2011; Vazire 2010). When this occurs, the people in our lives may try to push back on abnormal changes or shifts to our narrative identity, advising us when an external force appears controlling or pointing out any negative behaviors and actions that they've observed despite our own lack of self-awareness. While the people who care about us are often trying to change us for the better, sometimes their comments on our behavior or suggestions for change can seem too obtrusive to who we are and what we want to do in our lives.

As to whether or not these external opinions are truly beneficial is context-dependent, but having outside influences who can observe and comment on our behaviors allows us to constantly reevaluate and readjust our identity with the help of others; Baylis terms this "achieving equilibrium," the ability to balance our own "projected self-narrative" with the perceptions of others (Baylis, 2013). This self-narrative can also be heavily shaped by "our sense of ourselves as specific *kinds* of people," as members of specific groups that are crucial to our identity, such as groups related to careers, family member roles and responsibilities, as well as illness-related identities (Bluhm, Cabrera, and McKenzie, 2019; Lindemann, 2013), which may be particularly relevant to patients pursuing DBS. As the amount of people who have received DBS for refractory conditions is still relatively small, however, shared narratives from members of the group "DBS recipients" are lacking, especially given that it can be used for such a variety of conditions that it seems to be a new category of membership altogether. With this lack of existing narratives, it makes sense that patients would have difficulty adjusting to life after implantation—they might not have the language or "templates" that others experience to make sense of their own phenomenological experience.

To add to the complexity, these factors will also be informed by pre-treatment aspects of identity like patient relationships and priorities, making it crucial to ask patients directly about the experience of being a person treated with DBS so that they can examine how DBS may be impacting them and the stories they tell about their relationships, illness, and goals for life (Bluhm, Cabrera, and McKenzie, 2019). Especially in times of difficulty, like when dealing with chronic illness or health issues, those closest to us may play a crucial role in keeping us grounded; giving us people to lean on to maintain our sense of identity or to "hold" us in our identity. In other circumstances, when negative events impact our bodies or minds, others help us to create new identities in order to move on, heal, or grow (Goering, Brown, and Alsarraf, 2017).

In some cases, patients may undergo significant changes to aspects of their narrative identity post-DBS implantation without being able to identify such changes in themselves. Examples of this phenomenon have been noted in de Haan et al (2017), in which several patients became more impulsive and self-centered, and in Gilbert et al. (2017), in which family felt that they "didn't recognize" the patient; in both cases, while the patients' relatives were able to recognize their new negative behavior, the patients themselves did not report such changes. Kraemer (2013) reports the same phenomenon with authenticity as well, noting that third-party perspectives and ascriptions of authenticity and/or alienation of a patient can differ significantly from patient perspectives themselves. Some scholars have suggested that patients may need to recognize themselves once again or reidentify themselves after DBS has begun (Goering, 2014), rather than attempting to repair their narrative to its previous state.

By acknowledging the dynamic and relational nature of our identity in general, some scholars suggest that changes to our identity, even through external devices such as deep brain stimulation, may not actually need to be such a cause for concern (Baylis, 2013; Shoda, Tiernan, and Mischel, 2002). If DBS, for example, only affects one or few elements of an individual's complex and dynamic identity, then perhaps it would feel like less of a complete identity transformation or disruption, and more of a slight change or shift. Nevertheless, ethicists like Lipsman and Glannon have acknowledged that one of the more unique impacts of DBS on identity very well could be in those cases in which the patient's own perspective about the unchanged continuity of their selfhood and identity differs from, and needs to be reconciled with, the perspectives of their family who feel quite the opposite. This would seem in alignment with the idea that relational factors of identity are perhaps more important to personal narrative than continuity as experienced by the individual (Lipsman and Glannon, 2013). Though invaluable, self-perception produces an incomplete and distinctly nonobjective measure of identity. In the context of DBS, when patients are unable to recognize their own changes, caregivers and loved ones may be crucial for observing disturbances to narrative identity.

Role of Caregivers

As the importance of relational accounts of identity has been noted in the DBS literature, researchers have begun to explore caregiver perspectives relating to many aspects of the DBS process, including personality and identity changes. This concept is still somewhat novel, however, as a preliminary search in the literature yields comparatively few results for articles investigating caregivers' perspectives of DBS-induced changes to patients; some articles exploring personality changes to patients have utilized standardized assessments that incorporate ratings from caregivers, partners, or people in regular contact with the patient, while others have begun to take a qualitative approach with caregivers as well, asking them directly about identity and personality changes that they may have noticed in the patient (Brezovar et al., 2022; Bluhm, Cortright, Achtyes, & Cabrera, 2021; Chacon Gamez, Brugger, & Biller-Andorno, 2021; Thomson et al., 2021; Baumann-Vogel et al., 2020; Mosley et al., 2018; Lewis et al., 2015).

Despite these articles, more research needs to be done on caregiver perspectives relating to DBS generally as well as on personality and identity changes more specifically, especially considering what preliminary assessments of caregiver perspectives have revealed about patient post-DBS experiences (Witt et al., 2013). In Lewis et al.'s 2015 article, for example, personality changes were only identified in 6/27 (22%) of patients while they were recognized by 10/23 (44%) of caregivers, oftentimes due to the impacts that these changes had on the caregivers themselves. Similar impacts were seen to caregivers in Mosley et al. (2018), whose participants reported "feeling helpless and overwhelmed by the changes observed in their partner." Thomson et al. (2023) similarly emphasizes that caregivers "possessed valuable knowledge" of patients and were "well-positioned to provide observational feedback." With closeness and proximity to patients, and especially with sufficient training to make such observations, caregivers may be able to perceive changes with a higher accuracy, (Biesanz, West, & Millevoi, 2007), making them an important stakeholder group who can provide intimate insight into the prevalence and magnitude of the ethical concerns that they too are affected by.

Chapter 2: Methodology

Research Design

As noted in the first chapter, some scholars have argued that concerns regarding personality and identity changes after DBS are rooted primarily in theory and lack substantial empirical evidence, especially from a variety of stakeholder perspectives (Pugh et al., 2021; Gilbert, Viana, and Ineichen, 2021; Baylis, 2013). Only recently have such patient perspectives been a focus in DBS trials, with researchers beginning to investigate the personal experiences and narratives of patients rather than merely alleviating or reducing symptoms (Thomson et al., 2020; de Haan et al., 2017; de Haan et al., 2015; Lewis et al., 2015). Even fewer studies have included the perspectives of other stakeholders, such as clinicians and caregivers, who may also provide crucial insight into the prevalence and magnitude of these ethical concerns. Because of this, there is a clear knowledge gap and need for further empirical research to robustly depict personality and identity changes from the viewpoints of both patients and caregivers and to respond to such concerns appropriately. Whether or not the opinions of caregivers should factor into ethical discussions regarding the future use of DBS to elicit desirable, value-concordant changes to patient behavior is a crucial question that cannot possibly be answered without an understanding of caregiver perspectives and observations.

While it is imperative for future research to continue analyzing patient outcomes such as symptom reduction and overall quality of life after DBS implantation for a variety of disorders, this thesis focuses specifically on analyzing the ethical concerns of personality and identity. The primary aim is to explore the impact of DBS on patient personality and identity through the eyes of caregivers—an understudied stakeholder group in the academic literature—by identifying relevant themes and patterns and their frequencies in caregiver responses. Doing so may provide insight into the ways in which caregiver perspectives may contribute to patient narratives and experiences with DBS.

Study Organization and Data Collection

All aspects of study organization and data collection for this study were carried out by my collaborators[15]—a team of researchers at Baylor College of Medicine's Center for Medical Ethics and Health Policy and Harvard Medical School's Center for Bioethics– while I conducted data analysis. I utilized a qualitative approach to explore patient changes in domains frequently noted in the neuroethics literature, including quality of life, risk-taking, and authenticity and autonomy, personality and identity. Semi-structured qualitative interviews were conducted with caregivers (n = 20) of patients who had undergone surgery to implant an aDBS device for one of four conditions: obsessive compulsive disorder, Parkinson's disease, essential tremor, or Tourette syndrome. Table 1 shows a breakdown of caregivers and their respective patients' conditions.

Table 1. List of caregivers according to patient condition

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[15] I was originally connected with and worked alongside the research team via a summer internship at Baylor College of Medicine's Center for Medical Ethics and Health Policy. After helping with analysis for patient data from this study, and expressing my interest in caregiver responses, I was given access to and permission to analyze caregiver outputs specifically for this. This caregiver data has not been otherwise used for publication.

Caregiver ID	Patient Condition	Caregiver ID	Patient Condition	Caregiver ID	Patient Condition	Caregiver ID	Patient Condition
A_003	OCD	B_013	PD	C_016	ET	C_010	TS
A_005	OCD	B_016	PD	C_018	ET	C_012	TS
A_008	OCD	B_018	PD	C_020	ET	C_014	TS
A_010	OCD	B_020	PD			C_022	TS
A_013	OCD	B_023	PD				
		B_025	PD				
		B_027	PD				

The research team developed interview guides with the help of preliminary data from researchers, discussions with DBS researchers, and an exploration of the literature. The team used the interview guides to direct conversation during interviews but allowed for flexibility so that caregivers could elaborate upon their answers or lead discussion to other relevant topics. Interview guides assess perspectives on changes in personality, authenticity/selfhood, risk-taking, autonomy and quality of life as well as regret of the decision to undergo DBS. Given the subjective and complex nature of personality and identity-related concepts, open-ended questions allowed patients and caregivers to adequately articulate their perspectives and to utilize or integrate these terms into their own language about these topics (Leavy, 2020); no operationalized definition of personality or authenticity was articulated to patients. Interviews took place both pre-surgery, in May of 2019, and post-surgery, in March of 2020. For the purpose of this thesis, which aims to examine caregiver perspectives of patients' personality and identity changes specifically, questions utilized are limited to those that dealt with topics of personality and authenticity.[16] Pre-surgery, caregivers were asked generally about their concerns with and perceived benefits of DBS, what kind of effect they expected DBS to have on the patient's symptoms, and the overall quality of life experienced by the patient. They were also asked questions that more specifically referenced personality and identity-related concepts, such as whether or not the patient's condition had affected their personality or authenticity / ability to be the real them, and what kind of effect they predicted aDBS to have on the patient's personality, relationships, and risk-taking. Post-surgery, caregivers were asked about the actual effect that aDBS had on a patient's symptoms, relationships with others, quality of life, behavior and personality, risk-taking, and authenticity, and were encouraged to voice any concerns regarding patient behavior or device function / success. It should be noted that neither of the interview guides utilize the more abstract term "identity" explicitly; instead, as noted in Chapter 1, they refer more to selfhood, and use the terms "authenticity"—as in an individual's "authentic self"—and "the real me" to refer to the identity of the patient. This decision was made in an effort to utilize language more frequently found in the vocabulary of the public, but to still get at the notion of identity, which arguably has significant philosophical overlap with authenticity in the theoretical literature (see Chapter 1, *Changes to Self [and Authenticity]*).

Data Analysis

Interviews were recorded and transcribed verbatim. The research team created a preliminary codebook to identify excerpts of text in the transcripts that described changes to personality, authenticity, and identity, and all other themes present in the interview guides. For the purpose of this data analysis, only responses in which caregivers specifically referenced or

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[16] Pre-surgery and post-surgery interview guides (which can be viewed in Appendix A and B) were developed to explore themes beyond changes to patient personality, authenticity, and by extension, identity. The specific interview questions to be discussed in this paper have been bolded for clarity in the greater interview guides.

spoke generally about themes of personality, identity, self, behavior, or mood, were exported into code outputs from coded interview transcripts. Due to delays in transcription, one of the caregiver's responses were not included in data analysis, resulting in a final caregiver sample size of 19. I then performed thematic content analysis on outputs pertaining specifically to personality, authenticity, and identity (Vaismoradi, Jones, Turunen, and Snelgrove, 2016; Boyatzis, 1998). This process consisted of iterative abstractions and theme identification; in the first abstraction, participant responses were paraphrased as concisely and in as few words as possible, and in the second abstraction, the first abstraction was paraphrased even further, attempting to encapsulate the key points in the participants' response. Common themes and patterns were identified in participant responses and some frequencies were calculated to show the prevalence of certain responses. Data from pre- and post-DBS interviews are reported here.

Chapter 3: Results

Of the 20 caregivers that were interviewed, five (25%) were caregivers of patients with OCD, eight (40%) were caregivers of patients with PD, three (15%) were caregivers of patients with ET, and four (20%) were caregivers of patients with TS. Due to the small sample size of each group of caregivers per condition and the subsequent lack of generalizability, no comparisons were made between groups. Data analysis and results focus solely on comparing and contrasting experiences, perceptions, and narratives between caregivers as a whole.

3.1 Personality

Pre-surgery Interviews

During pre-surgery interviews, caregivers were asked about the effect that patient conditions had on their personality, what kind of effects or benefits they believed the aDBS would have on the patient and their personality, and what concerns they had about aDBS. Slightly over half of caregivers (10/19; 53%) reported that their loved one's disorder affected their personality, though one caregiver later noted the "real" problem as the patient's ability to function, rather than their condition. Although nine (47%) caregivers reported that their loved one's condition did not affect their personality, a few still reported behavioral changes, such as increased frustration, anxiety and depression, that they linked to the patient's condition. One caregiver in particular highlighted a diminishment in patient personality despite believing that it had ultimately stayed the same as before the patient's OCD onset. She described being able to "see it in his eyes" that his personality and mood had "gone down" in recent years (A_003).

When asked what kind of effects they predicted aDBS to have on patient personality, about half (9/19; 47%) raised concerns about aDBS drastically changing patient personality. Caregiver B_013, for example, listed mental changes to the patient's personality as one of her two biggest fears about aDBS: "This smart, funny, this wonderful guy, and I could live with the Parkinson's, I couldn't live with *that* being changed." Another caregiver's biggest fear consisted of a change in the lifestyle she shared with the patient and that they both enjoyed. She recalls the patient and herself worrying about "all of a sudden [him wanting] to be this person that's wanting to run around and be different" (A_010). On the other hand, some caregivers had doubts about aDBS's ability to return patients to pre-condition versions of themselves: "I can't imagine the DBS is going to set back the clock and make him like he used to be" (B_023). Of those who articulated what kind of effects they hoped or desired aDBS to have on patient personality, several caregivers spoke about the hope to see some kind of return to the patient's real personality, or a personality that they exhibited in the past:

> *"I hope her personality that I remember when she was a child comes back full force… I hope that part of her personality where she's outgoing and her smiling and laughing will come back. It's not there right now." (A_008)*
>
> *"I'm hoping he'll get back more like himself, or just happy. I want him to be happy." (A_003)*

Others reported desiring no change, or highlighted particular personality traits that they hoped would remain intact:

> *"I'm hoping not to see any change because I love him exactly the way he is." (B_013)*
>
> *"I'm hoping he keeps his dry sense of humor... and quick wit. I just hope he stays the same, I guess." (B_027)*

Post-surgery Interviews

When asked generally about the effect that aDBS has had on patients' behavior and personality, eight (42%) caregivers noted only positive effects, eight (42%) noted both positive and negative effects, two (11%) noted only negative effects, and one reported no effects on personality (5%). While the interview guide only asked specifically about personality and behaviors, caregivers also frequently referred to patients' mood. Some of the most common psychological benefits noted by caregivers included improved sociality / interpersonal relationships (n = 5), confidence (n = 8), sense of agency (n = 6), positive emotionality (n = 8) / seeming happier (n = 7), optimism / positive mindset (n = 5), openness to the world / others (n = 4), being more "present" (n = 3). Similarly to improvements in agency and being "present," some caregivers noticed increased engagement in work or hobbies. Regarding their loved one’s post-aDBS benefits, one caregiver said:

> *“I think he definitely seems more happier day to day, like I said about his emotional state, mental state, seem to be improving a lot. He's just not, I feel like his life doesn't really revolve around his Tourette's as much anymore” (C_022).*

Another respondent highlighted that the biggest effect of DBS had been on “her point of view. She is much more relaxed. She's got more of a sense of humor, now” (B_025).

Negative impacts on personality noted by caregivers occurred in similar rates to benefits but included unwanted negative emotionality (n = 7), isolation / decreased sociality (n = 4), anxiety (n = 3), lack of agency (n = 3), self-consciousness (n = 2), and diminished energy and motivation (n = 2). Table 2 (seen below) presents several examples of frequently observed negative changes.

Other changes noted when caregivers were asked about personality changes were more cognitive in nature, including difficulty focusing, extreme tiredness and severe memory loss, though only one caregiver considered these changes to be personality-altering (B_023). For one patient dealing with cognitive issues, a caregiver described differences in cognitive load and ability which lead to sensitivity and frustration:

> *“She can't really multitask the way she used to. Cognitively, she has to really focus in on one specific thing. She'll get flustered and she'll lash out a little bit. If I'm trying to have a conversation with her, but she's trying to focus on something, she'll lash out a little just because she can't process all that all at once” (B_020).*

Table 2. Negative personality / behavioral changes.

“He’s **rather detached**. He’s always been kind of detached, but **now he’s more so… Just from life.**” (B_027)

“Like **when he doesn’t feel good**, he just either lays down. He goes out in his little man cave office out in the backyard and **life stops for him.**” (B_023)
“...his symptoms were all better. But he was kind of **having a problem with taking initiative with some work, he was really kind of just getting more depressed**. Because even though he had the improved symptoms, he was **lacking the motivation.**” (B_018)
“...sometimes it’s up and down. **Sometimes she’ll be so angry** and I don’t know why. But she’s so angry sometimes. It’s just, if a feather falls off or dust falls, it’s like, oh my God. It **doesn’t take much** sometimes for her to become **very agitated and aggravated.**” (A_008)
“I need her to allow [the device] to benefit her more and believe in herself…The **self-esteem is at a low.**” (A_008)
“He **doesn’t really take care of himself**, and this is **so different from what he used to be** even when he was having OCD symptoms.” (A_003)
…he’s always had that little tenderness to him, I would call it, but **since the surgery it’s more so**. It’s us sitting in the living room and the sniffles or whatever, and I know that **he’s having a hard time as far as [emotions are concerned]** at that moment, but it passes…so that is a **change emotionally that I have noticed** in him.” (C_018)

Another caregiver described other negative cognitive changes such as spaciness and inability to focus, explaining that she often had to urge the patient to “stay in the moment” because “[she didn’t] know where his mind [was]” (B_023).

In addition to highlighting individual behavioral changes when asked about the effect of aDBS on patient personality, caregivers also frequently commented on whether or not aDBS had changed the patient’s personality more holistically. While almost every participant (18/19) noted some type of behavioral changes (reported above), only 6/19 respondents (33%) specifically reported an alteration or transformation of the patient’s personality from aDBS. Of these six, two reported a return to the patient’s pre-disorder personality while the other four described a general change to patient personality. Two of these individuals found the change to be negative, describing their loved ones as unengaged, somewhat depressed, detached (B_027), distant, and lacking motivation (B_018). Another respondent, who confirmed a change to personality but described a mixture of positive and negative changes, noted both increased agency and independence as well as irritation and pessimism (A_008). Caregiver C_014, on the other hand, found the change to be largely positive, observing openness and an improved attitude and mood. Out of those who gauged no overall change to patient personality (13/19), a handful opted to highlight characteristics or traits that had stayed the same post-surgery and appeared to play an anchoring role in patient personality (Table 3).

Table 3. Persistent patient characteristics post-DBS surgery.

"I don't think it's had any effect on his [personality] or anything at all. He's **always been a pretty open kid**… He's **still a fun-loving young man.**" (C_012)
"She's **always had [good relationships]** … She's **very outgoing, wonderful personality.**" (C_014)
"He's **always been a fairly positive person**. That **hasn't changed.**" (C_010)
"He **still has his sense of humor**, his quirky sense of humor." (B_027)
"No. I think he's pretty much the same. He's **always had a really good attitude.**" (B_016)
"He's **always been an outgoing guy**. And yeah, his **personality is the same.**" (B_013)
"It hasn't changed his personality or anything. He doesn't have outbursts. He never did. He's **always been a calm kind of guy.**" (C_016)

3.2 Identity-Related Concepts

Pre-surgery Interviews

While the term "identity" was not explicitly used during the interview process, caregivers were asked if the patient's disorder had changed the patient as a person and/or if the patient's conditions affected the degree to which they feel authentic or like the "real them." Responses from caregivers which made reference to selfhood, authenticity, "realness," and who the patient is or was as a person, were flagged as relevant to patient identity. During pre-surgery interviews, 7 (37%) caregivers referred to ways in which patient identity had been affected by their respective disorder (Table 4). Some caregivers considered these to be negative impacts that had changed patient behaviors, like C_012 who felt hurt seeing the patient in his current state, "[knowing] the kid he was before," or B_018, who actually felt that Parkinson's disease had "changed both [herself and the patient] because it's a big disruption."

Others referred to ways in which a patient's disorder had integrated with their identity. One caregiver in particular mentioned the patient's ability to be her authentic self when interacting socially, but that this only lasted for so long until she could no longer "hold back" her OCD (A_008) (other examples in Table 4). Additionally, a caregiver of a PD patient emphasized ways in which the patient's physical PD symptoms impacted their gender identity and masculinity, suggesting that aDBS implantation would make the patient "feel like a better man" (C_016). Other caregivers of patients with PD noted similar self-consciousness and self-estrangement from tremors and inability to perform normal tasks in public or social settings.

Table 4. Notable quotes regarding patient identity and their disorders pre-aDBS surgery

"[I]t's **hard for me to separate who he is** as a **person** and who he is as a **Parkinson's patient**." (B_023)
"He just **isolates…I can hardly remember what he was like before [Parkinson's]**, honestly, because it's been quite a while now." (B_023)
"Tourette's are just a **part of her**… she **wouldn't know what to do** if she didn't have Tourette's." (C_014)
"I think she just kind of **likes herself better with Tourette's**. [She] said that's just **who she is**. [She] kind of just **identifies with that**." (C_014)

“The real him is a weird term because **this is the real him, this is who he is. He has Parkinson’s disease…** [we have] very **different goals and priorities** and Parkinson’s has affected that.” (B_018)
“[I **don’t think she’s] herself** all of the time.” (A_005)
“...yes, it **changed her personality** and she became more, oh, I want to say not so nice to people. I think she's suffering so much that she **doesn't want people to get close to her**. And so that's how she keeps them at a distance, **being rude** and not so nice… [when meeting people] she is a **different person**.” (A_008)

Post-surgery Interviews

Of the 19 participants, 7 (37%) explicitly described a change in patient identity in the post-surgery interview. References to identity and authenticity came up throughout the interviews in relation to various questions, including whether or not DBS had changed the patient as a person, whether a patient’s behavior or personality had changed, what the patient’s quality of life was like post-surgery, and whether caregivers felt that the patient was authentic or the “real” them. Four caregivers (21%) indicated a return to the patient’s pre-disorder identity, whether that meant a particular trait had returned, such as gregariousness (C_016) or that the patient as a whole seemed more like their “old self” (this term is noted several times in Table 5). Some caregivers felt conflicted about reporting a full return to a patient’s “old self,” but willingly noted that a patient was in the process of coming back over time (B_027), or that they were “not too far off” from their old self (B_018). About half (8/19, 42%) of caregivers felt that patients had remained the same or had maintained the same identity post-surgery. Interestingly, two of these caregivers, neither of which ascribed a *new* identity to their loved one, joked about patients becoming cyborgs or part-machine and part-man (Table 6) despite claiming that patients were roughly the same person post-surgery. Neither of the caregivers seemed to ascribe any negativity to this integration of technology into patient identity. Without landing firmly in any of the three categories, one caregiver described their loved one as newly “free to be himself and do what he wants to do” post-aDBS surgery (B_013). Only a few caregivers (3/19, 16%) reported a new identity in patients, one of whom was not entirely confident in their assessment of the patient’s identity (see section 3.3). Alongside their descriptions of patients as appearing like a “different person,” caregivers noted increases in confidence and positivity (C_014), an improved world view and ability to relax (B_025), and an increased ability to participate in life (C_016). Four caregivers (4/19, 21%) did not articulate a clear opinion on identity changes seen in the patient.

Table 5. Caregiver perspectives of observed identity persistence post-surgery.

Becoming a different person
“I would say doing so much better. She’s **kind of like a different person**. She has confidence in herself. She has a different job. She loves it. So things are better. A lot better” (C_014).
Remaining the same person
“ I don't really think the device has changed him… “He’s **still the same old [patient.]**” (B_016).
“I don't think anybody would say, ‘Oh, geez. I notice a difference in you,’ or concern, that type of thing. I'd say no… **He’s himself**” (C_018).
“**I don’t think it’s altered** him and **who he is**” (C_012).
Returning to pre-disorder identity
“I find that his moods are better, and he's more positive and upbeat about that. So as each day passes and he gets stronger, **I feel the old [patient] is coming back.**” (B_027)
“I wouldn't say it's changed him as a person, I just think it's **allowed more of the positive qualities and mindsets to come out** that had kind of **been pushed down** by so many **years of the Tourette's** just keeping him down.” (C_022)
“I don't think it's changed him. I think it's **brought out who he was before he just got so depressed**. I don't think it's kind of changed him really, no.” (A_003)
“I think he’s **more like his old self** as far as cutting up laughing.” (A_003)
“It was just kind of a **return more to his own old self**… He’s more **like his pre-diagnosis self**, in mood as well.” (B_018)
“I just know that he's **back to his more gregarious self.**” (C_016)

“...he’s even happier now because he’s **free to be himself** and do what he wants to do…” (B_013).

Table 6. Further comments relating to the impact of DBS on identity.

Embracing cyborgism
“...my favorite comment when we were deciding about whether or not [to have the surgery] was, ‘Well, oh, he'd **be part machine**. He'd **be part computer, part man**.’” (B_018)
“And he always jokes, "**I'm a Cyborg or an alien**", or something, and [a guy] looked at him like, ‘What's up with your head?’” (A_010)
Emasculation and Confidence
“…we've been starting getting out more. He **feels more like a man**, he can stand and shake hands and **not be embarrassed**… it’s just been a **better life** for him.” (C_016)

3.3 Dimensionality of Identity and Personality Persistence

One pattern seen throughout the interviews was that caregivers often perceived patients as falling into overlapping categories when it came to personality and identity change. For some caregivers, this response was due to a general difficulty to articulate or characterize exactly what had changed about patients, with some even admitting that it was “hard to say” (C_020) whether personality or identity changes had taken place. For others, patients appeared to exhibit both personality- or identity-altering changes as well as a preservation of enough anchoring traits, behaviors, or values so as to maintain the same personality or identity. Because of this, some caregivers appeared to provide somewhat inconsistent responses related to patient changes. Caregiver C_016, along with several others displayed below, provides a perfect example of the ambiguity seen when discussing patient identity with caregivers. Throughout the course of this participant’s interview, they described the patient as back to his old self, absolutely the same person, and like a different person at the same time:

"He's absolutely the same person…Only happier…and better. More in control… his basic personality has not changed at all" (C_016)

"He's just a different person because…" (C_016)

"He's absolutely back to his more gregarious self…" (C_016)

Three other caregivers discussed patient identity similarly; one caregiver noted both no change to the patient as well as a return to who the patient was before (C_022), and another acknowledged that after surgery, their loved one was "just herself…just a positive type person now, and fun to be around. Which, she [hadn't] always been " (C_014). When asked about the patient's quality of life after surgery, the same caregiver referred to the patient as being "like a different person" (C_014). The third caregiver also emphasized being able to see that aDBS had changed the patient as a person, but also described seeing her as [the same patient as before] even with the device on" (A_008). Some caregivers made sweeping statements about changes to patient identity (that they are different, the same, or that they returned to their old self), yet discussed the observance of only slight or minimal changes to the patient, such as becoming more relaxed (B_025). Other cases of this occurred with caregiver A_008, who also confirmed that DBS had changed the patient's personality, but who stated that it "[depended] on what month it is." Other caregivers were somewhere in between, confirming that their loved one had moved somewhat in one direction, but did not seem confident that they fit fully into any of the three previously mentioned categories. Caregiver B_027, for example, pointed out that "[the patient] is more back to regular [patient]" but that she and her daughter still "feel that he's detached" to an extent that was an important and noticeable change.

3.4 Changes Perceived by Others

Interviewers also asked caregivers if others had perceived changes to patient personality and identity. Responses from participants varied along a spectrum, ranging from other family members and friends noticing the same changes seen by caregivers, to only the caregiver being able to pick up on personality and identity changes. Interestingly, one caregiver in particular described their loved one as a "lone wolf," emphasizing the fact that other individuals would not be able to notice any changes to the patient because people do not know who he really is. Even as his caregiver and spouse, she admitted that she "[doesn't] know him much better than when [they] got married, other than what [she] observed," largely because the patient keeps to himself (B_023). Contrastingly, another caregiver highlighted their ability to observe changes within the patient that he may not have noticed himself. The respondent described these positive changes such as increased confidence and sociality, acknowledging that these changes are somewhat external, and explaining that they may be "things that [the patient] wouldn't really think about or notice in himself, but [that she] definitely noticed" (C_022). Table 7 provides more examples of participant responses regarding external perception of personality and identity changes.

Table 7. Personality and identity changes perceived by others.

"I think **definitely his family, who he lived with, can see the change**. His **friends also**, they notice. A lot of them knew that he was having the surgery so they understand why. I think they **definitely have noticed** that he's a lot, in better spirits… trying to engage more in things that he enjoys." (C_022)
"Some **family members have commented on her attitude** and all that…I don't know about individuals other than family… I've told her how significant it is, [the changes in her]." (C_014)

“Well, yeah **[other people] notice he doesn't wiggle anymore**. And maybe a little **more lightness** to him. Before, he did his best not to be self-conscious, but he was. And now he's **carefree, there's not that self-consciousness** anymore about anything.” (B_013)
“She's still the same person. She's just happier… Her **sister has the same observations** that I do, I think.” (A_005)
“No, **[family members] see pretty much the same thing I do**, that he's still just the same loving kid he always has been.” (C_012)
“So I guess **to [other people]** it's the **same old [patient].**” (C_020)
“No, I don’t think [others see a change]. I think it’s **mainly just me.**” (B_020)
“He **does not show it to people**, honestly. People just **don’t know [patient]**.” (B_023)

Chapter 4: Discussion

The aim of the research questions in this study were to qualitatively examine the impact of aDBS implantation on patient personality and identity from the perspective of caregivers. I have characterized the valence, frequency, and quality of changes observed by caregivers of patients who have received aDBS, and gathered perspectives on the contribution of such changes to patient interpersonal relationships and life after surgery. To my knowledge, this study is one of few investigations of caregiver perspectives of personality and identity changes post-DBS with insights on patients both prospectively and retrospectively—giving us a baseline to better inform postoperative changes—and provides a first-hand, qualitative, primary study account of experiential aspects of post-DBS neuropsychiatric symptoms and changes to patient identity and personality.

Changes observed in this study by caregivers are largely consistent with those documented in the existing literature by both patients and caregivers, including the finding of mixed results – both positive and negative changes—to patient personality and identity following

DBS implantation. The ratio of negative changes to positive changes also appears to roughly mirror those reported by other studies (Merner et al., 2023), with responses overall leaning towards more positive, restorative changes, like feeling happier, more confident, and more optimistic. While several caregivers did report negative changes in dimensions of patient personality, they did not appear to express significant distress about these impacts being destructive or detrimental to patient identity or personality. The types of personality and identity changes noted by caregivers and their impact on patients post-DBS will be explored further in the context of the theoretical literature below.

Personality Changes

According to caregivers, patients exhibited a range of both positive and negative changes to personality, spanning from mood / behavioral changes, to social and interpersonal changes, to cognitive changes, which overlap heavily with changes established in the empirical literature (Merner et al., 2023, Thomson et al.,2023; Thomson et al., 2020; Ramasubu et al., 2021; de Haan et al., 2017). The two most commonly reported negative concerns included negative emotionality, such as increased irritation, anger, or frustration, and issues with sociality, including detachment, isolation, and other interpersonal issues. Descriptions of patients “up and down behavior”, being quick to aggravate or irritate, and ultimately detaching or isolating from the difficulties of their condition even post-DBS bare a resemblance to the interpersonal conflict and negative emotionality issues seen in previous studies (Thomson et al., 2023; Houeto et al., Ashkan et al., 2013; Agid et al., 2006; Houeto et al. 2002).

Although only two caregivers found negative changes in dimensions of personality drastic enough to classify the patient’s personality as “different” post-DBS, smaller negative changes were still identified by almost half of respondents and led to a degree of worry and concern in caregivers, including dealing with patient anger and aggression, lack of self-care /hygiene and patient disconnection, i.e. feeling like patients are not engaged with their life or family (see Table 2). Notably, several (8/19) caregivers emphasized perceiving both positive and negative changes to personality in patients, acknowledging that some dimensions of personality like having an improved sense of agency could also coincide with remaining negative emotionality and frustrations. These caregivers recognized that DBS had both improved some aspects of personality that contributed to an overall increased quality of life, while detracting from others. pointing to the complexities of trying to assess overall improvement or success for patients post-DBS.

Indeed, the potential for patient personality to change was a fear raised by about half of caregivers pre-surgery, and was best illustrated by responses from caregivers B_013 and A_010. Both caregivers detailed specific aspects of patients that they would be reluctant or afraid to lose, from B_013's emphasis on the patient's "wonderful" intelligence and humor, to A_010's concern over losing the patient's particular disposition and thus lifestyle that they had curated and been enjoying together for years. From a caregiver's perspective, experiencing changes to patient personality affects more than just the patient and what personality traits define them, it also causes subsequent impacts to the shared life that a caregiver has had and has curated with that patient specifically. Caregivers made a point to articulate that patients were loved exactly as they were, and that they didn't want the person that they had chosen to build a life with to change post-DBS; B_013 even stated that they would willingly live with Parkinson's (and all of its symptoms and difficulties), but "couldn't live with" their loved one's personality being changed. These relationships stand to be significantly impacted by changes to patient personality, how they behave, and how they interact with their caregiver (which has also been noted and evidenced in the literature; Guelke and Poetter-Nerger, 2022; Baumann-Vogel, 2020; van Hienen et al., 2020) and concerns raised by caregivers in this study reflect that. We see this universal fear play out in modern media and other contexts as well. In popular novels Bewilderment by Richard Powers and Flowers for Algernon by Daniel Keyes, main characters Robin and Charlie endure experimental therapies (one consisting of neurofeedback and the other surgical in nature) to help manage neuropsychiatric conditions and elevate IQ (respectively). While we follow Charlie's perspective throughout the novel, getting a direct glimpse into the changes he perceives to be taking place in his personality, as a child, Robin's father and primary caregiver is the one who notices and worries deeply about Robin's changes (Keyes, 1959). In one chapter, he thinks to himself: "I was running a calculation I didn't know how to complete. How different was [Robin] from who he'd been months ago? He'd always sketched, always been curious, always loved living things, but the boy at my right elbow was a *different species*[17] from the boy who'd played with his birthday microscope in our rented cabin in the woods a year earlier," even referring to both "old" Robin and "new" Robin as the neurofeedback worked to reduce his neuropsychiatric difficulties (Powers, 2021). Despite the behavioral benefits of the therapy, we see Robin's father struggling with the balance between wanting his own son's life to be easier, safer, and happier, and feeling as though he has lost something vital to what makes Robin who he is in the process. Indeed, some caregivers alluded to the need to find a similar balance, with A_003 stating that they hoped the patient would "get back more like himself," but doubling back to emphasize that more than anything, they would want the patient to be happy post-implantation, regardless of what changes occurred.

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[17] Italics added.

As I mentioned previously, one of the biggest remaining questions in the personality and identity change debate has to do with how we know or gauge that a personality has normatively and significantly changed such that it is no longer the same personality as before (Baylis, 2013; Schermer, 2011; Glannon, 2009). Interestingly, of those caregivers who felt that patient personality had stayed the same, many offered up their own sort of justification as to "why," highlighting particular traits or characteristics that they felt had carried over from pre-DBS patient to post-DBS patient. In a way, caregivers used these traits as evidence that patient personalities had stayed intact (Table 3). While these traits are unlikely to be the *only* important traits or characteristics that anchor an individual's personality, for example, most trait theories of personality incorporate a spectrum of five to 26 traits that show up in individuals to varying degrees (Cattell, 2001; John, Donahue, and Kentle, 1991; Iowa Scales of Personality Change), we can think of these particular "anchoring" traits as at least part of the core, foundational, more stable traits that make up an individual's expressed personality over time. Examples of "anchoring" traits to these caregivers included openness, an outgoing disposition, a positive outlook and attitude, a good sense of humor, and being calm, several of which are reflected in the attitudes and traits in existing personality measurement tools (John, Donahue, and Kentle, 1991). Caregivers' instinct to highlight what they see as persistent aspects of patient personality raises interesting questions about the way that patients perceive their own most foundational and stable traits, whether they would assign the same value to traits highlighted by caregivers as core or if they would cast them off as more peripheral, and the different value or weight of each perspective. It may very well be that a caregiver and surrounding loved ones consider a patient's defining characteristic to be their conscientiousness, whereas the patient considers herself to be inattentive and in need of work on that particular trait. If the patient does not perceive any kind of change in their conscientiousness post-DBS, but everyone else around them does, and feels affected by it, do these opinions matter? Does it matter to the patient that the personality their loved ones considered them to have has changed? Does the caregivers' perspective have ethical significance that deems it worthy of consideration? Should caregiver perspectives factor into the ethical calculus done by patients when they consider stimulation in the first place or continuation of stimulation? For some patients, these external perspectives may not matter at all, as long as the patient herself is satisfied with the changes; for others however, the knowledge of being perceived as different in established, cherished relationships and its subsequent impact on the strength of those relationships may be enough to warrant more meaningful conversations between stakeholders to raise awareness of and illuminate perceived changes and how (if necessary) to handle them.

Identity-Related Changes

Like with personality, identity-related changes reported by caregivers were comparable to the changes identified and evidenced in the current empirical literature. Pre-surgery, caregivers reported concerns related to patient self-image and self-perception (Gilbert et al., 2017; Gilbert, 2012), as well as feelings of self-consciousness, especially in patients with PD, who often experienced obvious, debilitating physical symptoms that prevented them from completing simple tasks or engaging in physical and social activities that they desired. One caregiver specifically commented on the impact of PD on the patient's masculinity, suggesting that it had impacted his ability to fulfill the masculine roles of "husband" or "partner" that he had previously occupied for years (C_016). These issues contributed to negative self-perception and a sort of self-estrangement from who patients felt that they used to be before diagnosis with their condition.

Changes to identity-related concepts largely fell into three categories: 1) a return to pre-disorder or previous patient identity, 2) maintaining the same identity or 3) development of a new identity. In addition to more holistic changes in patient identity, While caregivers reported on a sort of negative, deteriorative self-estrangement in patients pre-DBS, they were also able to pick up on changes to patient identity and authenticity post-DBS. A majority of caregivers who recognized an identity change in patients post-DBS reported a more positive return to pre-disorder self, highlighting particular qualities that had returned in the patient, as well as describing how the effects of patient symptoms had dissipated to allow the patient's previous identity to shine through once again. One caregiver, for example, stated that the patient post-DBS was now "free to be himself" (B_013), potentially after a removal of the patient's illness identity or any constraints from condition symptoms that prevented them from living in accordance with their true or real self. Pugh (2020) describes this idea as an opportunity to "rediscover the [true self] after it has been overshadowed by years of chronic illness." Other studies have referred to this return-to-previous-self phenomenon as a sort of restorative self-estrangement—one in which an individual or those around them recognizes that they are not the same person as they were at one point in time, but have had certain qualities restored that return them to a previous selfhood or version of themselves (Gilbert, 2017b).

Notably, Gilbert (2017b) also suggests that this kind of restorative estrangement can occur in degrees, with certain aspects or features of a patient's identity returning to the way they were in prior selfhood, while other aspects of qualitative character remained hindered or dampened. This idea of changing in degrees may provide a useful framework for some of the caregiver responses from this study, in which caregivers recognized crucial aspects of patient identity changing that made them feel as though the patient was returning to their pre-condition self, like returning to a more positive attitude or gregariousness, while acknowledging that other characteristics of patients had not quite made the return yet: “I think he is not the same fun-loving guy as college quite, but not too far from that… [but] he's more like his pre-diagnosis self, in mood as well (B_018).

Dimensionality of Personality and Identity Change

In addition to some caregivers feeling as though patients’ identities lay somewhere in between their illness identity and their pre-condition identity, a handful of caregivers organized patient changes to identity into all three categories at once. On the one hand, these descriptions of patient identity changes may be interpreted as inconsistencies, in which caregivers were unsure of how to characterize or capture a patient’s current identity, and thus described it one way when answering a certain question and another way entirely in response to a different question, but on the other hand, they may also be viewed as purposeful classifications, in which caregivers perceived patients identity to be multi-faceted, such that different aspects of it fell into each of the categories. As to whether or not it is feasible for patients to experience a simultaneous return to their “old” self *and* creation / development of a “new” self, more degreed or leveled approaches to identity a la Gilbert (2017b) may account for such a possibility, in which case an individual’s cluster of core and peripheral values, goals, and beliefs may experience concomitant piecemeal changes in opposing directions. Moreover, the same phenomenon may occur in patients who overwhelmingly experience a return to their pre-condition, authentic self, but still struggle with adjustments necessary for returning to “normal life” post-DBS implantation. Such challenges may manifest in behavioral differences that patients and caregivers feel do not align with patient identity, and may even seem sufficient to constitute a “different” person (Pugh, 2020).

De Haan et al.(2017) reported similar ambiguities in patient responses post-DBS, such as patients who utilized opposing language to communicate the same answer to the question, “did you change, as a person?” They describe two patients who technically answer the question differently—yes I changed, versus no, I did not change—but who actually provide essentially the same answer, semantically—that they aligned more with or became more of their “real” self. While one patient considered this alignment to mean that they had become a different person, because they had reached a new, real version of themselves that they had not attained or inhabited before, the other felt as though they were not different, given that the changes merely assisted in showing the patient’s actual, underlying identity without the overshadowing of their condition (de Haan et al., 2017). Though we can’t be certain that these patients had the exact same experience of “becoming closer to their real self,” it appears that their own intrinsic definitions of what it means to “change as a person,” were disparate, causing them to exhibit contrasting answers despite parallel experiences. Thus, in much the same way that philosophers continue to debate ways to define “identity,” “self,” and what aspects might constitute changes to these concepts, it is unclear how much the reported experiences of patients and the observations of those experiences by caregivers really differ from one another, as well as to what extent these differences can actually be chocked up to variations in individual categorizations and terminology (de Haan, 2017).

Despite the challenge that this issue places on methodological approaches to investigating qualitative reports of identity and personality changes, it also points to the value of and ongoing need to more robustly catalog the type of “layman’s” language utilized by both patients and caregivers when conceptualizing and describing changes to identity and personality in patients. After all, it is these conceptualizations that stakeholders factor into their own deliberations about the harm and disruption posed by such changes to patient personality, identity, and quality of life post-DBS, not the abstract definitions and nuances of such concepts proposed by philosophers. Despite philosophers' and ethicists' suggestions that "subtle" changes may not be enough to bring about a change in identity, we must acknowledge that patients and caregivers have their own thresholds for and understandings of what amount or magnitude of change needs to take place for patients to assume a "different" identity, and if a patient says that an aggregation of subtle changes have resulted in a "different" person post-DBS, what good are philosophical definitions to refute this experience? Because of this, it may be that solidifying the academic, philosophical categorizations and conceptualizations of these changes is actually less important for improvements in measurement and language standardization than understanding these concepts as the public understands them, so that we can better help patients who feel that their behavior is not in alignment with their values, desires, interests, or previous self-conception. The ambiguity seen in caregiver responses about identity and personality change in this study point to the need for more in-depth probes and explorations into caregiver, as well as patient, conceptions of identity and personality; doing so might allow us to learn more about the reasoning and considerations behind their inclusion / exclusion criteria for certain traits or characteristics as key components of personality or identity, what common language may be used synonymously with and in lieu of what academics consider to be "identity," and how stakeholders' perspectives of these concepts may differ culturally and socially. As Nyholm (2018) aptly notes, this might be a crucial way of acknowledging and recognizing stakeholders' own important and perhaps widespread attitudes and thoughts about these concepts, despite them not always being easy or robustly articulable (Nyholm, 2018). Validating patient and caregiver-defined accounts of personality and identity and matching their own operationalized language about these concepts may improve future communication and understanding between those experiencing and observing such changes and those attempting to measure and capture them.

Relational Identity and the Value of External Perspectives

Beyond their own assessments, caregivers were also asked about whether they thought other people, i.e. other family members or friends, had made similar assessments or perceived similar changes (or lack of changes) to patient personality and identity. Caregiver responses from Table 7 illustrate the spectrum along which other family members of friends recognized and acknowledged changes in patients. Along one end of the spectrum, caregivers who noticed no changes to patients themselves corroborated such opinions with similar testimony from other people interacting with the patient. In a similar vein, several caregivers who did report changes to patient personality or identity also listed other family members, including sisters and daughters, who had comparable observations. Some even made a point to vocalize such changes to caregivers or patients themselves. Family members along with caregiver C_014, for example, made sure to "comment" on noticeable changes to the patient's attitude, as well as reiterate to the patient herself "how significant" the changes had been, while another caregiver remarked on their ability to pick up on things like more external, positive changes to the patient that they had not even thought about or considered. In this way, the patient's caregiver and family members may be contributing to the rebuilding and reconceptualization of identity taking place in the patient as they integrate the opinions of others and determine which to incorporate or endorse (Baylis, 2013).

Interestingly, two caregivers felt that others were or would be unable to recognize changes in the patient even though they had occurred. For individuals who are naturally more private, insular, or just generally less outwardly expressive of their inner emotions, desires, interests, values, and other features that play a role in outward expressions of personality or identity (like the patient of B_023), it may be that detrimental changes are harder to recognize for more peripheral or distant family members or friends. In this case, even the caregiver and spouse of the patient had doubts about her ability to pick up on critical changes. In these cases, patients may be their own best proxy for identifying experienced changes that feel significant or disruptive to their existing identity or personality. Nevertheless, B_023's caregiver had existing awareness of the difficulty of really "knowing" the patient and was still able to contribute to the discussion on patient changes, identifying a concerning level of detachment from the patient that had worsened with DBS and was impacting her and her family.

Caregiver B_020 stated that it was "mainly" just them who recognized changes to the patient. Although this caregiver did suggest that social distancing may have played a role in this (interviews took place during a more heightened portion of the COVID-19 pandemic), they also acknowledged that the patient's newfound irritation, impatience, and bouts of frustration had particularly been released in their presence, suggesting that the patient was maybe more open about displaying such behaviors with their caregiver. Even if it is the case that only caregiver B_020 would have been able to identity such changes in the patient, their constant time spent with the patient (being isolated in the same house together over time) does speak to a caregiver's ability to recognize changes through close and constant proximity and their value in recognizing significant or detrimental changes to patient personality or identity.

Ultimately, both caregivers and other loved ones can utilize their knowledge and relational understanding of a patient's identity to make their own determinations about the value or detriment of certain changes to patients' fundamental identity or personality. Although it is imperative to emphasize that caregivers' perspectives of patients' personality and identity change post-DBS should not replace or outweigh the testimonial and experiential perspectives of patients themselves, these findings have confirmed and supplemented the caregiver perspective on patient personality and identity change in the empirical literature, and have shown their value—that caregivers have and can effectively capture many of the prominent themes and perspectives reflected by patients on this issue. With this ability, caregivers provide an additional, valuable perspective to at the least, supplement those provided by patients themselves.

A Way Forward? Caregiver Perspective in DBS Decision-Making

As I have explored in Chapter 1, much of the scholarship on post-DBS personality and identity change in recent years has been focused on providing robust enough empirical evidence to either establish or dismiss the notion that DBS-induced changes pose a significantly normative threat to patient identity and personality, such that this potential harm should be a stronger consideration in the risk/benefit analysis needed to decide on pursuing DBS. While empirical studies have shown that changes of a magnitude so large that they may cast doubt on the decision to receive DBS will not be a problem for a majority of patients who undergo it, the concerns raised by both patients and caregivers in previous studies as well as this study are genuine and have at the least demonstrated that personality and identity change is a probable experience for any patient considering DBS implantation. For this reason alone, it is worthwhile to continue exploring stakeholder perspectives on the side effects of DBS treatment on feelings of identity, selfhood, and personality, and I argue, to better incorporate these perspectives into decision-making about DBS implantation and allow patients and their caregivers to engage in thoughtful reflection and robust communication about the kind of outcomes they are hoping to achieve (and avoid) with DBS treatment.

To this aim, I propose the introduction of a collaborative values identification exercise and care conversation during the education and decision-making process for DBS implantation. Specifically, I have developed a worksheet that allows patients and caregivers to discuss *together* and more specifically the values, goals, preferences, and features central to the patient that they hope DBS will not change from the patient's pre-DBS to post-DBS self. Such a worksheet pulls from models of shared decision-making that traditionally focus on discussions between patients and their healthcare providers, in which patients are encouraged to reflect on and identify values, preferences, priorities, and goals of treatment or care that they can then bring to conversations with a member of the healthcare team in order to have a more collaborative discussion—with their own interests in mind—to find the best fitting option to proceed (Montori et al., 2023). While the shared decision-making model is traditionally considered to occur between patients and healthcare providers specifically, perhaps with caregivers weighing in informally from the sidelines or as desired, this approach brings caregiver perspectives to the forefront, to be considered alongside patients' perceptions of their own values, goals, personality, and identity. Aligning with theories of relational identity, this approach recognizes that the desires, beliefs, values, intentions, actions, and experiences that make up a person's self-narrative and identity are shaped by and through relationships (Baylis, 2013), and that as influences on / shapers of identity, caregivers can assist patients in recognizing them. As caregivers and patients engage in this introspection before DBS, they can make determinations about the authentic, foundational, load-bearing values of the patient as well as features or aspects of the patient's personality and identity that they believe are paramount and crucial for still feeling or appearing like themselves post-DBS. Doing so can provide an established baseline or reference point for patients and caregivers to think back to post-DBS as they attempt to qualitatively assess whether changes feel in-line with patient values, identity, and authenticity. In fact, both Pugh (2020) and Nyholm and O’Neill (2016) have suggested that valuable reference points for a patient’s true self may come from a source other than the patient, like a third party assessment, rather than the patient’s condition-influenced mindset and self-perception.

It is important to note that while I see value in caregivers becoming more incorporated into the decision-making process and conversations to pursue DBS, I do not suggest that caregiver consent should be required for a patient to move forward with the treatment; ideally, patient preferences themselves would be determinative of the extent of caregiver involvement. Critics may still argue that the decision to pursue or proceed with deep brain stimulation for any number of conditions should be a completely independent and individually autonomous decision for the patient experiencing such conditions and symptoms, i.e. that a caregiver’s own perception of patient personality and identity and tolerance levels for change should not matter for a patient’s decision to undergo DBS implantation. Of course, we currently employ such a mindset and prioritization of patient autonomy in medical decision-making (should the patient have established capacity) for all medical interventions, especially those that are considered to be invasive and life-altering (Shah et al., 2023). In line with this thinking, some critics may suggest that caregivers’ opinions should not carry any more weight especially in DBS decisions than in traditional clinical decision-making for a variety of reasons, like the potential for caregiver burden to bias caregivers to encourage or nudge patients towards DBS implantation in an effort to alleviate whatever strain a patient’s condition has put on the caregiver or family’s own lifestyle and well-being (Cavallieri et al., 2023; Guelke and Poetter-Nerger, 2023), or because when given the chance, caregivers may voice a low tolerance for any type or magnitude of negative change in the patient, throwing off the necessary risk/benefit calculus in these conversations.

To push back on this notion, however, the concept of relational autonomy is instructive. Relational autonomy acknowledges the individual as socially-embedded, recognizing that people develop and form their sense of self, values, beliefs, preferences and commitments through relationships and in relation to others on a daily and long-term basis" (Bell, 2020; Dove et al., 2017). This concept asserts that relationships are crucial for developing and promoting autonomy, and in the clinical context, it encourages us to guide decision-making by an "ethic of care and moral responsibility," accounting for our social situation to promote both our own flourishing as well as that of our social environment (i.e. our loved ones and those closest to us) (Dove et al., 2017).

In contexts such as oncology, critical care, and end-of-life, we see this concept play out in patients who place importance in communicating about treatment options with family members, with 89% of oncology patients preferring to make medical decisions jointly with family members and oncologists in one study, and almost half of patients in a survey of over 5000 people with lung or colorectal cancer responded that they would want family members involved in decision-making (Laryionava et al., 2018; Schaefer et al., 2006; Reiter-Theil, 2003). Patients have even reported feeling less anxiety, distress, and improved quality of life over decisions to forego medical treatment that were arrived at with the help of family involvement (Newell, Sanson-Fisher, and Savolainen, 2002). For patients facing significant enough negative changes to identity or personality post-DBS, the difficult cost/benefit calculus of whether or not to discontinue stimulation may be made easier or at least less anxiety-inducing by discussions with caregivers who are able to provide their own experiential perspective on the matter. Caregivers also often report a willingness to participate in care, with one study noting that caregivers felt well-equipped with experiential knowledge of the patient so as to contribute to more holistic care and a more positive care experience for both patients and their families (Belanger, Desmartis, and Coulombe, 2018). Family opinions also often have a significant impact on patient preferences and decisions for treatment (Zhang and Siminoff, 2003), and for some patients, can become a priority in their decision-making. When asked to rank their values at the end-of-life alongside family members, for example, both patients and family members ranked values such as family, partner, and children in their top three in the Schaefer et al. (2006) survey, suggesting that for some patient-caregiver dyads, values may already be closely aligned for reaching consensus about goals of treatment and care (Sedig, 2017). With certain conditions or in certain contexts at least, patients may actually prioritize incorporating family member's or caregivers wishes, values, or preferences in their decision-making. Even when values are incongruent between patients and their caregivers, however, conversations between patients and their loved ones can help to facilitate understanding of each party's goals for treatment and care and in some cases, what a patient's loved one wants or hopes for them may ultimately become integrated into their own authentic desires. In this way, by recognizing and acknowledging the relational context in which our own values and preferences were created, Ho (2008) argues that consideration of family interests and family involvement in decision-making can be essential in promoting patients' agency.

While the quality of life and subjective, lived illness experience of patients is paramount to this decision given that they are the ones directly impacted by such an invasive intervention, it is important to emphasize that these decisions do not occur in a vacuum—a wealth of established reports prove how significantly side effects of DBS implantation can impact interpersonal relationship dynamics, causing pressure on and conflict in marriages (sometimes leading to divorce), impacts on patient willingness or general motivation to participate in family roles and responsibilities, and highlighted in this study especially, general detachment and isolation from family and life, which can breed similar detachment and depression in caregivers (Boulicault et al., 2023; Clausen, 2010). Given this, I push back against the idea of shutting caregivers out of risk/benefits analysis and decision-making for DBS altogether and argue that caregivers stand to offer valuable and insightful contributions to patient considerations necessary for undergoing DBS as well as better identifying and recognizing value-discordant changes post-implantation. Examples of existing value-driven worksheets and exercises can be seen in decision aids for patients with advanced heart failure deciding whether to receive a left ventricular assist device implantation as well as for patients at the end of life deciding what they want their death or the steps leading up to it to look like (LVAD and Your Values; End of Life Washington). Useful for this application, the LVAD decision aid's section on identification of values allows patients to rate and articulate which values matter most in their decision-making, including things like improvement of physical symptoms, elongation of life, and avoiding certain complications like stroke. Using this values exercise as a model and utilizing the breadth of studies exploring effects of DBS on patient behavior, mood, personality, authenticity, relations and more to inform the kind of effects that can take place after DBS implantation, Appendix A and B provide very preliminary mock-ups of what this values exercise could look like for patients and caregivers deciding on DBS. This exercise, when bolstered by the existing methodologies for assessing patient personality and identity including pre- and post- surgery assessments of patient personality from both stakeholder groups using established standardized measurements (described in Chapter 1) as well as the qualitative, subjective explorations of patient and caregiver perceptions of impacts of DBS on their personality, identity, and related concepts, provides two main benefits: 1) a more robust glimpse into patient-caregiver dyads' ideas of successful versus harmful post-DBS outcomes and impacts that they may or may not be willing to tolerate (which may differ between stakeholders), and 2) a more informed baseline for patient-caregiver dyads to refer back to and use to engage in thoughtful conversations about the impacts of DBS implantation, whether they are cause for concern, and their overall impact on patient (and by extension caregiver) quality of life. Although these proposed worksheets do not explicitly ask for patients and caregivers to describe how they conceptualize identity and personality–which as I mentioned earlier may be an important next step for cataloging the language of these stakeholders–it does ask stakeholders directly what they see as fundamental components of their or their loved ones identity and personality, providing a starting point for insights into what kinds of traits, characteristics and values hold particular import for the public when considering these topics.

In Practice

Having patients and their caregivers fill out their own values worksheets separately, and then coming together for meaningful, safe conversation about their answers allows dyads to explore where their perspectives align and diverge, and what these alignments and divergences should mean for their plan to pursue or continue DBS. For example, though most patients choose to continue with neurostimulation despite slight unwanted changes to aspects of their lives, and may seek out adjustments to stimulation parameters, some patients may choose to discontinue DBS and explant (Gilbert, 2015b), and once a device is explanted, the side effects of stimulation may dissipate.[18] In this context, patients and caregivers may want to seek out explantation to experience a return to their previous personality or to "get back" to their pre-DBS status. Given that DBS may have serious benefits to patient symptom reduction alongside such negative or unwanted changes in states of mind, making the decision to discontinue stimulation is often a hard one, with patients having to weigh benefits with other undesirable changes that may be impacting their quality of life. What this value exercise may do, then, is allow patients and caregivers to preemptively identify the types or caliber of changes that they feel would warrant discontinuation of DBS versus others that they would deem justified by physical or functional benefits achieved by the device. Additionally, identifying these threshold-tipping values or characteristics pre-implantation allows dyads to plan for how they want to handle such changes post-implantation while the patient is still in their "unchanged" state. Take for example a patient who becomes irritable and isolated post-DBS, but who fails to recognize their behavior and how it has been negatively impacting their caregiver (spouse) and children. Some caregivers in this position may feel that their loved one would consider discontinuation of stimulation if they could only see the impact their new behavior was having on their relationships and overall quality of life, but getting the post-implant patient to see this may prove difficult. Although the proposed values exercise cannot measure changes in the way that standardized assessments have been working to do, caregivers who perceive such changes in patients post-DBS can point to values previously identified by dyad-consensus as worthy of prioritization over stimulation in an effort to open a discussion with patients and perhaps to remind them of agreed upon values and

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[18] Despite reversibility of side effects being seen in some DBS patients who have explanted for other reasons, like infection, misplaced leads or battery problems, to my knowledge there is not yet a literature exploring the "reversibility" of changes to personality or identity post-DBS explantation and recent articles have provided more evidence to suggest that side effects following the cessation of chronic DBS may not be as reversible as previously thought (Kroneberg et al., 2022).

priorities for maintaining a shared quality of life post-DBS. At the same time, however, patients do not need to take measures as drastic as explantation of their DBS device for the value exercise and subsequent reflection to be beneficial; it would be just as meaningful for patients and caregivers to game plan about how to handle changes to patient personality and identity that make one or both parties unhappy in other ways, like the emergence of certain character changes provoking visits to a personal therapist or couples therapist to adjust to a patient's new personality or self as well as just increased awareness[19] of more identity-altering changes to encourage more understanding and empathetic interactions and discussions between caregivers and post-DBS patients about how such changes are impacting quality of life. For these reasons, caregiver perspectives are instructive considerations to incorporate into value-identification and decision-making conversations for DBS.

In recent years, scholars attempting to understand the nature of personality and identity changes and their normative significance to patients have been exploring ways to improve methodological approaches to capturing such changes in depth. Pugh (2020) suggests the need for more interview-based studies involving patients, caregivers, *and* family members across the treatment timeline to get a more complete picture of new behaviors or characteristics seen in

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[19] Indeed, we can look to the concept of implicit bias to see the value of increased awareness of how we behave or act. Individuals with implicit bias have their own subconscious perceptions, attitudes, feelings, and perhaps stereotypes or prejudices that influence their decision-making and actions in the world (Shah and Bohlen, 2024). Because these personally held perceptions and attitudes are subconscious, people are often ignorant of their own implicit biases until someone else identifies them. As a matter of fact, raising awareness and bringing implicit bias to an individual's attention is considered to be a crucial first step for reducing or eliminating such bias (Lee, 2017). Like with implicit bias, patients who remain unaware of post-DBS changes to their personality and identity may be unknowingly causing harm to their caregivers, families, and other relationships. While incorporating the perspective of caregivers in decision-making and value-identification conversations pre-DBS implantation and in reflective discussions about observed changes will not stop or prevent them from happening in the first place, it will give caregivers the opportunity to raise awareness of such changes which– especially for those patients who fail to recognize their own differences and the impacts of such differences on their loved ones–will hopefully serve as a first step towards addressing these changes in a way that is sufficient for that patient-caregiver dyad and the people around them.

patients, more context to inform patients' judgments and perceptions of experiencing such changes, as well as clearer answers to what patients themselves think it is to become a different person. Calls for and attempts at using more of a mixed-method approach of measuring changes have also only recently become more common, focusing on the combination of quantitative, qualitative, and conceptual explorations of these changes (Allen, Giordano, and Okun, 2023; Snoek et al., 2021; Kubu et al., 2019); Witt et al. (2013) suggests more of a combination of empirical, quantitative data alongside testimonies from caregivers and patients about their subjective experiences. Some have suggested the construction of entirely new, objective tools for evaluating patients' behavior and related concepts that are able to reflect and account for personal self-ascriptions of patient authenticity and identity (Gilbert et al., 2021; Kraemer, 2013). While some studies have also proposed the measurement of patient values and goals before and throughout DBS treatment to attain more multifaceted assessments of patient outcomes (Kubu et al., 2018; Kubu and Ford, 2017; Kubu and Ford, 2012), none thus far have aimed to integrate a self-directed assessment of both patient and caregiver values and perspectives on personality and identity-related concepts specific to the patient to ensure only value-congruent changes.

Limitations

This study has several limitations that need to be acknowledged. Firstly, this patient sample included those dealing with both neurological and neuropsychiatric conditions, which complicates our ability to make direct comparisons between negative changes to identity and personality experienced by the two groups. As noted by Hoy et al. (2023), combining elements typically regarded as distinctly "neurologic" and "psychiatric" when generalizing across conditions may obscure important nuances and neuroethical considerations. The areas of the brain targeted and the complexity of neurostimulation for psychiatric conditions can differ substantially from those for neurological disorders, potentially impacting the nature and severity of any personality or identity changes. Additionally, while this study is one of the first to examine stakeholder perspectives on aDBS implantation, analyses were limited in their ability to assess the impact of device type on the results. As such, the discussion and all recommendations were made for DBS more generally. As highlighted by Allen et al. (2023), the lack of a comparison cohort of patients who received older, open-loop DBS devices hinders our ability to empirically understand whether aDBS systems differentially impact personality and identity compared to traditional DBS. Future research is needed for a proper comparison between the impact of device types on patient identity, personality, and especially authenticity and agency, as those concepts have been flagged for concern in the ethical literature. Furthermore, the present thesis focused solely on qualitative responses from caregivers taken from a larger project that also examined quantitative and qualitative data from patients. Given that patients were asked similar questions about personality and identity-related concepts both pre- and post-DBS implantation, future work should aim to integrate and compare caregiver and patient perspectives, as caregivers' perceptions of personality and identity changes may differ in meaningful ways from patients' own conceptions of their selfhood and personality. While this study provides valuable insights into caregiver perspectives, more research is needed to elucidate the value of these perspectives and how they can be mapped onto and integrated with patients' experiences. Findings could be used to inform the values-centered conversations that I propose before DBS implantation; such conversations are crucial for ensuring that patients are fully informed about the potential for personality and identity changes and can make autonomous decisions aligned with their values and preferences.

Conclusion

This study underscores the valuable perspectives that caregivers can offer in understanding changes to patient personality, identity, and related concepts following DBS. Although patients and caregivers are at least made aware of the potential for such postoperative changes, we currently lack a meaningful understanding of how both stakeholder groups comprehend these concepts and perceive and measure what they deem essential to their own and each other's personality and identity. Moving forward, efforts must be made to allow patients and caregivers to articulate for themselves and in their own language what changes to patient identity and personality constitute a significant, normative impact on the self for them and what changes may align with versus disrupt current values and preferences. My suggested approach, to provide a structured exercise for patient-caregiver dyads to reflect on what specific aspects of personality and identity are most central to their or their loved one's sense of self, offers at the least a valuable opportunity before undergoing DBS for patients and their caregivers to start a dialogue about potential changes that they may deem harmful or undesirable. These perspectives may then inform decision-making processes for patients and caregivers as well as establish more personalized benchmarks for monitoring and evaluating post-DBS changes and their impacts on patient quality of life. Such an approach holds promise for achieving values-concordant care and giving patients and caregivers a tool to better prepare themselves for making more informed care decisions about how to respond to potentially negative impacts to patient personality and identity post-DBS. . As new generations of DBS and other neurotechnologies continue to advance, developing a nuanced, individualized understanding of these abstract, yet universal concepts will be essential for promoting patient well-being post-neuromodulation.

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Appendix A

Staying “True to You” with DBS

There is evidence to suggest that some patients undergoing deep brain stimulation for a variety of conditions experience post-DBS changes to personality, behavior, mood, identity, feelings of authenticity, and self-perception. Thinking about the values below and then discussing them with your caregiver may help to identify characteristics of who you are that are worth prioritizing and observing should you move forward with DBS treatment.

You can use the lines below to write down your thoughts.
When you are finished, talk through the answers with your caregiver.

Aspects of my personality that I feel like have been lost to or overshadowed by my condition include: ____

Aspects of my personality that I value and consider to be fundamental to who I am include:
____

Some values, goals, or characteristics that I consider to be central to who I am include:
____

How important to you are the following items?

Feeling like I've maintained the core aspects of my personality outlined above

Very important Not important
5 4 3 2 1

My caregiver feeling like I've maintained the core aspects of my personality outlined above

Very important Not important
5 4 3 2 1

Feeling like I've maintained the values, goals, or characteristics that I/we consider to be central to my identity

Very important Not important
5 4 3 2 1

My caregiver feeling like I've maintained the values, goals, or characteristics that I/we consider to be central to my identity

Very important Not important

5 4 3 2 1

Feeling like my behaviors and actions are authentic

Very important Not important
5 4 3 2 1

My caregiver feeling like my behaviors and actions are authentic

Very important Not important
5 4 3 2 1

Participating in family roles and responsibilities

Very important Not important
5 4 3 2 1

Maintaining my current relationships (caregiver, marriage, children, other family members, friends)

Very important Not important
5 4 3 2 1

Being present and wanting to spend time with my loved ones

Very important Not important
5 4 3 2 1

Preventing isolation or detachment (from people, previous interests, etc)

Very important Not important
5 4 3 2 1

Maintaining the same outlook on life

Very important Not important
5 4 3 2 1

Appendix B

Staying “True to You” with DBS

There is evidence to suggest that some caregivers of patients undergoing deep brain stimulation for a variety of conditions perceive post-DBS changes to patient personality, behavior, mood, identity, feelings of authenticity, and self-perception. Thinking about the values below and then discussing them with your loved one may help to identify characteristics of who they are that are worth prioritizing and observing should they move forward with DBS treatment.

You can use the lines below to write down your thoughts.
When you are finished, talk through the answers with your loved one.

Aspects of my loved one's personality that I feel like have been lost to or overshadowed by their condition include: ____

Aspects of my loved one's personality that I value and consider to be fundamental to who they are include:

____

Some values, goals or characteristics that I associate with who my loved one is include:

____

How important to you are the following items?

My loved one feeling like they have maintained the core aspects of their personality

Very important Not important
5 4 3 2 1

Feeling like my loved one has maintained the core aspects of their personality that I have outlined above

Very important Not important
5 4 3 2 1

My loved one feeling like they have maintained the values, goals, or characteristics that they consider to be central to their identity

Very important Not important
5 4 3 2 1

Feeling like my loved one has maintained the values, goals, or characteristics that I consider to be central to their identity

Very important Not important
5 4 3 2 1

My loved one feeling like their behaviors and actions are authentic

Very important Not important
5 4 3 2 1

Feeling like my loved one’s behaviors and actions are authentic

Very important Not important
5 4 3 2 1

My loved one participating in family roles and responsibilities

Very important Not important
5 4 3 2 1

My loved one maintaining current relationships (caregiver, marriage, children, other family members, friends)

Very important Not important
5 4 3 2 1

My loved one being present and wanting to spend time with other loved ones

Very important Not important
5 4 3 2 1

Preventing my loved one from isolation or detachment (from people, previous interests, etc)

Very important Not important
5 4 3 2 1

My loved one maintaining the same outlook on life

Very important Not important
5 4 3 2 1